DOCUMENT RESUME

ED 470 529 EC 308 811

AUTHOR	Worthington, Janice E.; Hernandez, Mario; Friedman, Bob; Uzzell, Douglas
TITLE	Learning from Families: Identifying Service Strategies for Success. Systems of Care: Promising Practices in Children's Mental Health, 2001 Series.
INSTITUTION	American Institutes for Research, Washington, DC. Center for Effective Collaboration and Practice.; University of South Florida, Tampa. Research and Training Center for Children's Mental Health.
SPONS AGENCY	Substance Abuse and Mental Health Services Administration (DHHS/PHS), Rockville, MD. Center for Mental Health Services.; National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.; Special Education Programs (ED/OSERS), Washington, DC.
REPORT NO	Vol-2
PUB DATE	2001-00-00
NOTE	96p.; Part of the Comprehensive Community Mental Health Services for Children and Their Families Program. Produced with Ruby Joseph, James E. MacAlister, Kathleen Hague-Armstrong, Eloise Boterf, Tracie Goff, and Canice Tolin.
CONTRACT	H237T60005
AVAILABLE FROM	American Institutes for Research, Center for Effective Collaboration and Practice, 1000 Thomas Jefferson St., NW, Suite 400, Washington, DC 20007. Tel: 888-457-1551 (Toll Free); Fax: 202-944-5455; e-mail: center@air.org; Web site: http://www.air.org/cecp. For full text: http://www.air.org/cecp/new_products.htm.
PUB TYPE	Reports - Research (143)
EDRS PRICE	EDRS Price MF01/PC04 Plus Postage.
DESCRIPTORS	Agency Cooperation; Ancillary School Services; *Behavior Disorders; Case Studies; Cooperative Planning; *Delivery Systems; Elementary Secondary Education; *Emotional Disturbances; Family Needs; *Family Programs; *Family School Relationship; Inclusive Schools; *Integrated Services; Interdisciplinary Approach; Mental Health Programs; Program Design; Program Effectiveness; School Community Programs

ABSTRACT

This document is part of a series designed to provide guidance for communities and caregivers interested in building exemplary systems of care for children with serious emotional disturbances. The monographs show that the Comprehensive Community Mental Health Services for Children and Their Families Program has evaluated and developed promising practices and directly improves the health and lives of children and families throughout the country. This volume examines the success stories of 34 families with children who suffer from emotional and behavioral disorders. In the grant communities studied, "success" seemed to occur when the following elements were present: (1) families were fully engaged in services; (2) providers listened to families' priorities and addressed the highest priorities first; (3) services addressed the needs of the entire family; (4) services were designed on the basis of the families' identified strengths and

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needs; (5) services promoted and strengthened the connection between family and community; (6) providers were persistent in meeting families' needs and were fully accessible; (6) services were flexible and provided nontraditional supports; and (7) services provided opportunities for family empowerment. Appendices discuss the benefits of parent involvement in the study. (Contains 38 references.) (CR)

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Systems of Care
Promising Practices in Children's Mental Health
2001 Series

VOLUME II
LEARNING FROM FAMILIES: IDENTIFYING SERVICE STRATEGIES FOR SUCCESS

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Suggested citation:
Worthington, J., Hernandez, M., Friedman B., & Uzzell, D. (2001). *Systems of Care: Promising Practices in Children's Mental Health, 2001 Series, Volume II*. Washington, D.C.: Center for Effective Collaboration and Practice, American Institutes for Research.

The writing of all Volumes in the 2001 *Promising Practices* series was funded by the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, United States Department of Health and Human Services. This Volume was written by the Research and Training Center for Children's Mental Health at the University of South Florida, which is supported by the Center for Mental Health Services, as well as the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education. Production of the document was coordinated by the Center for Effective Collaboration and Practice at the American Institutes for Research, funded under a cooperative agreement with the Office of Special Education Programs, Office of Special Education and Rehabilitative Services, United States Department of Education, with additional support from the Child, Adolescent, and Family Branch, Center for Mental Health Services, Substance Abuse and Mental Health Administration, United States Department of Health and Human Services (grant number H237T60005). The content of this publication does not necessarily reflect the views or policies of the funding agencies and should not be regarded as such.

TABLE OF CONTENTS

EXECUTIVE SUMMARY **13**

Introduction 13
Study Design 13
Summary of Findings 14
Implications for Promoting Family Success 16
Endnotes 17

CHAPTER 1: INTRODUCTION **19**

Overview 19
Orientation to This Report 21
What the Research Literature Says About Successful Outcomes and Family Involvement in Service Delivery 22
Parent Involvement in Service Delivery 22
Defining Effective Service Delivery 23
Characteristics of Effective Parent-Provider Partnerships 23
Characteristics of the Provider 23
Characteristics of the Program or Service 26
Developing Parent and Professional Partnerships 26
Challenges of Developing Parent-Professional Relationships 26
Advances in the Parent-Professional Relationship 26
Benefits of Parent Involvement 28
Summary 29

CHAPTER 2: METHODOLOGY **31**

Study Purpose and Objectives 31
Study Design 31
The Role of Parent Research Assistants 32
Site Selection 33
The North Dakota Partnerships 34
Southwest Detroit Community Mental Health Services, Inc., Detroit, Michigan 35
Guilford Initiative for Training and Treatment Services Site (GIFTTS), Greensboro, North Carolina 35
Multiagency Integrated System of Care (MISC), Santa Barbara, California 35
Community Wraparound Initiative (CWI), Three Township Site, Oak Park, Illinois 36
Data Collection 36
Data Analysis 37

CHAPTER 3: DESCRIPTION OF STUDY PARTICIPANTS **39**

Profile of Participating Families 39
Ethnic Representation 41
Marital Status 42

Employment 42
Age of Child 43
Children's Special Education Status 43
Repeated Grades 44
Age When Problem Was Recognized 45
Person Who First Recognized the Problem 45
Age of Child When Services Were Initially Received 45
Child Diagnoses 46
Profile of Participating Service Providers 46

CHAPTER 4: WHAT IS "SUCCESS?" MAKING THE TERM OPERATIONAL 49

Family Hopes and Dreams 49
Understanding Success 50
Individual Achievements Versus Comprehensive Change 50
Achieving Goals and Meeting Basic Needs 50
Success in School 51
Interpersonal Relationships and Self-Esteem 52
Independence 52

CHAPTER 5: STRATEGIES THAT PROMISE SUCCESS FOR CHILDREN AND FAMILIES IN A SYSTEM OF CARE 55

Engagement 56
Meeting Basic Needs 56
Parents as Partners 57
Delivery of Clinical Services 59
The Successful Therapeutic Relationship 60
Collateral Clinical Services 64
Medication 65
Maintaining a Commitment to Family Goals 66
Structural and Operational Characteristics 67
Flexible Funding 68
Community-Located Services 69
Continuity of Care 69
Advocacy 70
Coordination of Care 71
Training and Education 72
Natural and Community Supports 73

CHAPTER 6: CONCLUSIONS 75

Engagement 76
Clinical Services 77
Structural and Operational Characteristics 78
A Paradox for Further Investigation 79
Implications 80

REFERENCES 83

APPENDIX A: GRANT COMMUNITY PROFILES **87**

The North Dakota Partnership 87
Bismarck, North Dakota 87
Fargo, North Dakota—Region V Partnership 88
Southwest Detroit Community Mental Health Services, Inc., Detroit, Michigan 89
Guilford Initiative for Training and Treatment Services Site (GIFTTS) Greensboro, North Carolina 90
Multiagency Integrated System of Care (MISC) Santa Barbara, California 90
Community Wraparound Initiative (CWI), Three Township Site, Oak Park, Illinois 91

APPENDIX B: BENEFITS OF PARENT INVOLVEMENT IN STUDY **95**

Experiences of Our Parent Partners 95
Stories of Mothers Caring for Children With Special Needs 95
Benefits of Having Parent Partners in the Study 96
Benefits of the Study to the Parent Partners 97

APPENDIX C: FAMILY INVITATION FLYER **99**

ENDNOTES **101**

FOREWORD

It is with great pleasure that we present the third collection of monographs of the *Systems of Care: Promising Practices in Children's Mental Health* of the Comprehensive Community Mental Health Services for Children and Their Families Program. The 2001 Series is a time of new beginnings for this seven-year-old federal grant program, which assists communities in building fully inclusive organized systems of care for children who are experiencing a serious emotional disturbance and their families. It also represents a year of validation and pride for those who have been involved with this movement for years. As more and more evidence on the effectiveness of the system of care approach amasses, we have been able to gain increased support to expand the number of grant communities and the investigation of promising practices within those communities. Owing to the proven success of the Comprehensive Community Mental Health Services for Children and Their Families Program, this year's budget reauthorization afforded our grant communities an extension of their grants, thereby expanding their community-based initiatives from five-year to six-year programs.

In his millennium report on Mental Health, Surgeon General David Satcher stated, "Across the Nation, certain mental health services are in consistently short supply. These include the following: wraparound services for children with serious emotional problems and multisystemic treatment. Both treatment strategies should actively involve the participation of the multiple health, social service, educational, and other community resources that play a role in ensuring the health and well-being of children and their families." Our grant communities employ these effective approaches in combination with other community-based strategies to help these children and their families thrive. As those of us fortunate enough to participate in this initiative grow and learn, we maintain a commitment to share our knowledge and resources with all communities.

Until recently, throughout this nation, and especially in Native American communities, most children living with a serious emotional disturbance have not received clinically, socially, or culturally appropriate care. These young people have been systematically denied the opportunity to share in the home, community, and educational life that their peers often take for granted. Instead, these children live lives fraught with separation from family and community, being placed in residential treatment centers or in-patient psychiatric centers hundreds and even thousands of miles away from their home. For many of these young people, families, and communities, the absence of certain types of information has fueled the continued existence of inadequate and unresponsive service delivery systems. Staff at these service delivery networks often believe that they have no alternative but to separate these children from their families and place them in costly, long-term, out-of-home placement. The *Promising Practices* Initiative is one small step to ensure that all Americans can have the latest available information about how best to help serve and support children who live with serious mental health problems at home and in their community.

Systems of Care: Promising Practices in Children's Mental Health is an annual publication that features the strengths of the systems of care being developed in this country through the support of the Comprehensive Community Mental Health Services for Children and Their Families Program. The grant program has helped develop cutting-edge technologies for forming effective systems of care throughout this country. The *Promising Practices* monograph series is a way for us to inform the thousands of communities that do not have the benefit of participation in the grant program about the emerging approaches and innovations occurring in systems of care. The *Promising Practices* series provides

guidance for communities and care givers interested in building exemplary systems of care and gives system builders the latest available information about how best to help serve and support children who live with serious emotional disturbances at home and in their communities. The monographs show that the Comprehensive Community Mental Health Services for Children and Their Families Program has evaluated and developed promising practices that represent an invaluable return on the nation's investment. Used in the grant communities, the *Promising Practices* series has clearly enhanced, and will continue to directly improve, the health and lives of children and families throughout the country.

Emerging systems of care within communities will certainly benefit the national knowledge base on how best to support the mental health needs of children who present major challenges, especially the contributions made by the grant communities themselves. We are proud that the information contained within these monographs has been garnered within the grant communities of the Comprehensive Community Mental Health Services for Children and Their Families Program. The information was gathered by visiting sites, holding focus groups, collecting data by the national program evaluation involving all grantees, and interviewing numerous professionals and parents.

The 2001 *Promising Practices* series includes the following volumes:

- *Volume I—Wraparound: Stories From the Field* explores the ever-burgeoning conviction by a growing community of providers, advocates, and families that Wraparound is simply better, cheaper, and more humane than conventional service delivery processes for families with children with serious emotional disturbance. Through the stories of six families who have received individualized services and supports through a Wraparound process, we see how this process worked to support their strengths and meet their needs.

- *Volume II—Promising Practices in Early Childhood Mental Health* shows us that systems of care serving very young children and their families are finding innovative and effective ways to design and deliver services. The authors consistently found that an approach to services that takes into account the whole child, including his or her family and community, his or her unique developmental needs and strengths, and his or her well-being in a variety of contexts is especially important and most effective. They also found that a truly family-centered approach to care with a high level of parent participation in decision making seems to increase the overall level of parent engagement in the well-being of their child within a particular child-serving agency.

- *Volume III—Learning From Families: Identifying Service Strategies for Success* examines the success stories of families with children who suffer from emotional and behavioral disorders. Family success, defined from the perspectives of the families and providers, occurs when systems of care focus on the entire family, meet families "where they are," and emphasize the connection between the family and their community. The monograph emphasizes the crucial importance of strong bonds between families and providers.

As you read through each volume, you may have a sense that some topics you would like to read about are not to be found in this series. We would expect that to happen simply because so many issues need to be addressed. We fully expect this series of documents to become part of the culture of this critical

program. If a specific topic is not here today, look for it tomorrow. In fact, let us know your thoughts on what would be most helpful to you as you go about ensuring that all children have a chance to have their mental health needs met within their home and community.

The communities that have been fortunate enough to participate in our federally funded initiative have been able to incubate solutions and promising practices that work! This series represents a gift of collective knowledge and lessons learned from our grant communities to those struggling to develop effective systems of care throughout the nation.

So the 2001 *Promising Practices* series is now yours to read, share, discuss, debate, analyze, and use. Our hope is that the information contained throughout this series stretches your thinking and results in your being more able to realize our collective dream that all children, no matter how difficult their disability, can be served in a quality manner within the context of their home and community. COMMUNITIES CAN!

Joseph Autry
Acting Administrator
Substance Abuse and Mental Health
Services Administration

Bernard Arons
Director
Center for Mental Health Services

ACKNOWLEDGMENTS

The Promising Practices 2001 series is the culmination of the efforts of many individuals and organizations that committed endless hours participating in the many interviews, meetings, phone calls, and drafting of the documents that you see represented here. Special appreciation goes to all the people involved in the grants of the Comprehensive Community Mental Health Services for Children and Their Families Program for going beyond the call of duty to make this effort successful. This activity was not in the grant announcement when they applied! Also a big thank you to all the writing teams that have had to meet deadline after deadline in order to put this together in a timely fashion. Not only did they work hard but also, as you can see, their efforts yielded great results. The staff of the Child, Adolescent and Family Branch deserve a big thank you for their support of the grantees and me in keeping this effort moving forward under the crunch of so many other activities that seems to make days blend into months. Thanks to David Osher, Cecily Darden, and their staff at the Center for Effective Collaboration and Practice for overseeing the production of the third series, specifically, Eric Spears and Diedra White for word processing and graphic layout support; Holly Baker for carefully editing all the monographs during the final production phases; and Huda Aden and Sarah Leffler for assisting in editing and proofreading. Finally, a special thanks to Dr. Dorothy Webman, who had the dubious pleasure of trying to coordinate this huge effort from the onset. Dorothy was able to put a smile on a difficult challenge and rise to the occasion. Many people have commented that her commitment to the task helped them keep moving forward to a successful completion.

AUTHORS' ACKNOWLEDGMENTS

Many individuals contributed to the research and writing of this project. Janice Worthington, Dr. Douglas Uzzell, Dr. James E. MacAlister, Ruby Joseph, and Dr. Kathleen Hague-Armstrong serve on the faculty and staff of the Department of Child and Family Studies at the Louis de la Parte Florida Mental Health Institute (FMHI) at the University of South Florida in Tampa. Special thanks are extended to Dr. Mario Hernandez, Dr. Bob Friedman, and Dr. Sharon Hodges for their expert guidance and advice as well as their encouragement and support. The study benefited from the participation of several parent research assistants, Eloise Boterf, Tracie Goff, Rene Anderson, and Sheila Allen, as well as Canice Tolin, a Parent Coordinator and Family Advocate from the Stark County (Ohio) Family Council, and Deloris Vaughn, a graduate student in the Department of Psychology at the University of South Florida. Grateful appreciation is also extended to Maridelys Detres of FMHI, who translated data-collection materials into Spanish and served as the Spanish-speaking interviewer in Santa Barbara.

In addition, this project benefited from the insight of two outside readers. Charlotte Williams is a family representative on the Stark County (Ohio) Family Council's Board of Trustees and Family Advocate with FACES (Family Advocacy and Community Education Equals Support) of Stark County. Donna Steeby is a parent advocate with KanFocus, the CMHS program in Kansas. These readers were not involved in the project design for this study or the data collection and analysis. They were asked to read the monograph to provide critical feedback when it was in draft form to ensure its clarity, its completeness, and its ability to speak to the issues and needs of families and the service provider community. Their assistance is very much appreciated.

The study team extends its thanks to the Child, Adolescent and Family branch of the Center for Mental Health Services. Special thanks are extended to the five participating grant communities, which responded quickly to a time-sensitive request for their participation. They identified and scheduled families for interviews rapidly and provided invaluable on-site support to the interview teams. In addition, their review of the monograph in draft form provided important feedback in ensuring the accuracy of the information presented.

The team is also grateful for the assistance of several of FMHI's support staff, who applied their skills in editing, desktop publishing, word processing, and coordination to the project: Kathy Anthony, MaryAna Farrar, and Nancy Burrus.

EXECUTIVE SUMMARY

INTRODUCTION

This monograph examines the success stories of families with children who suffer from emotional and behavioral disorders—and of the providers who work with them—to learn which services and approaches show the most promise. It identifies and describes promising practices in mental health services for children and their families. The practices examined are associated with family "success" in grant communities funded by the federal Center for Mental Health Services (CMHS) as part of the Comprehensive Community Mental Health Services for Children and Their Families Program.

Family success was defined from the perspectives of the families themselves and of the providers. Investigators documented the criteria the programs used to identify successful families, interviewed key providers and families, and distilled a working definition of success from the responses. Families and providers then identified the specific services and service approaches that they believe have been most effective in helping families achieve their goals.

Over time, the provision of services as part of a community-based, family-centered System of Care has dealt effectively with the problems of emotionally disturbed children. Just which services worked in that situation and how they worked, however, have remained a kind of "black box." The study on which this monograph is based begins illuminating the interior of that black box by learning which practices seem promising and under what circumstances.

STUDY DESIGN

A preliminary review of the literature built a beginning framework for understanding families' perspectives of effective service delivery. The literature also provided some insight into the qualities of successful family/provider relationships.[i] Specifically, the literature documented various individual qualities, professional perspectives, and specific supports that families perceive as facilitating a successful relationship. The literature did not yield information concerning families' definition of success. However, researchers learned much about the importance of families' expanding role as full partners with providers in the service-delivery process.[ii, iii]

Thirty-four in-person interviews with primary care givers were completed in five grant communities. In one community, an additional eight primary care givers participated in a focus group. At least two providers were interviewed in person in each grant community. The questioning route for both families and providers was semistructured and open-ended, which allowed participants to use their own words to

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describe their experiences and express their opinions. Participating grant communities were chosen to reflect the variety of contexts in which systems reform is occurring, including rural, small cities/counties, and urban communities.

The following questions guided this research:

- How are successful outcomes for children and families with severe emotional disturbances defined?
- What are the specific services or service responses that contribute to successful outcomes for children?
- What are the strategies that are effective in engaging and maintaining families' involvement in services?
- What are the supports and relationships most critical in promoting family success?
- What characterizes the successful therapeutic relationship and how does this relationship contribute to successful outcomes?

SUMMARY OF FINDINGS

In addition to the definition of success that was meaningful to both families and providers, consistent themes emerged to identify practices for achieving that success. Certain supportive and therapeutic services were frequently mentioned, but the factors that made them promising had as much to do with how services were delivered as with which services were delivered.

Briefly, the findings revealed that promising practices could usefully be classified according to the following functional categories:

- Engagement—the process of connecting with and maintaining the involvement of children and families in services
- Delivery of Clinical Services—service elements that lead to the development of effective family/provider relationships and ultimately promote success
- Structural and Operational Characteristics—specific features of services that demonstrate system values, including flexibility and a family- and community-based orientation

The monograph summarizes families' definition of success by describing the hopes they have for their children and the family as a whole and the accomplishments they have already achieved. It then identifies and describes the service approaches and direct services that families and providers perceived to be the most important in helping them achieve their goals. In an effort to give voice to families, direct quotes are heavily used, along with the comments of service providers, to describe what families believe is really working at the level of service delivery. It is worth noting that across grant communities and among all respondents, the practices identified showed a great deal of consistency.

Families consistently credited their success to the grant communities' approach to services, which they described as focusing on the entire family, meeting families "where they are," and emphasizing the connection between the family and the community. Although families tended not to use either the term "approach" or System of Care terminology, their awareness of the format of system delivery strongly supports three key principles generally considered indispensable in a System of Care. The activity must be

- child centered and family centered,
- individualized, and
- community based.

In each of the five grant communities, these principles appeared to constitute the context for all aspects of service delivery.

Strong bonds between families and providers appeared to be critical, whether the providers were case managers, therapists, parent advocates, or other staff. These bonds had their beginning in the engagement process. Reflecting some of the literature, providers built trust and confidence by listening carefully to what families identified as their primary needs and treated family members as full partners in the treatment process, focusing on their strengths rather than on their deficits.[iv] Meeting families' basic needs for housing, food, and medical care early on allowed providers to devote attention to other important resources and problems.

Grant communities built engagement through the relationships developed between the families and program staff, a process described in the literature.[v,vi] Families identified these relationships as their most important source of support. Unlimited access to providers and a depth of caring equal to that of the parents were primary features of these relationships.[vii] In many cases, providers were perceived as "family" and "friends." Families tended to rely on these providers for help in making decisions, locating resources, and obtaining crisis assistance.

Building on the existing literature that notes the importance of family involvement in service delivery, in many cases, families who were treated as partners learned case management techniques themselves.[viii] Not only did they learn to seek their own support, but some families also spoke of using the process of planning and progress review as a way to achieve their stated goals and as an opportunity to build skills. Many families adopted the process in their homes to improve communication with their children and to become organized. They also used these skills with teachers and administrators when addressing their children's problems in school.

Other features of services, such as flexible funding and the program staff's persistence and creativity in meeting needs, prompted families to refer to their providers as "miracle workers." They credited providers with finding innovative ways to gain support in the community to satisfy even the most simple and practical needs. At the same time, providers were strengthening the connection between families and their communities. By supporting children's recreational activities, for example, the grant communities successfully enhanced positive peer-to-peer relationships. A mark of success often mentioned was that children were "fitting in" with their peers and demonstrating an interest in friendships and activities.

Clinical interventions, such as psychotherapy, counseling, and psychopharmacology, also played an important role in family success. At their most effective, these services were provided in a context in which boundaries and status were relatively relaxed. The evidence of a trend toward conducting therapy in nontraditional locations, such as the family home, seemed to be growing. Given this context and the nature of the interactions, families did not refer to their providers as "therapists" or use any other title, but rather spoke of them on a first-name basis.

IMPLICATIONS FOR PROMOTING FAMILY SUCCESS

Studying family success within a System of Care offers an opportunity to consider implications for other systems striving to effectively serve children with emotional disturbance and their families. Although participants and grant communities consistently identified several promising practices being implemented at the level of direct care, the implications for other programs are limited because of the small number of interviews. In addition, this study made no comparisons with families who are not successful or who are being served outside the System of Care.

In the grant communities studied, "success" seemed to occur when the following elements were present:

- Families were fully engaged in services.
- Providers listened carefully and respectfully to families' priorities—and addressed the highest priorities first and promptly.
- Services addressed the needs of the entire family.
- Services were designed on the basis of the families' identified strengths and needs, as well as on their criteria for success.
- Services promoted and strengthened the connection between family and community.
- Providers, both individuals and teams, demonstrated genuine caring and were persistent and creative in meeting families' needs. Most important, they were fully accessible to families, often 24 hours a day, seven days a week.
- Services were flexible and provided additional supports not typically found in the rational approaches to service provision.

- Services provided opportunities for family empowerment, learning, and skill building. Through this process, families were given the chance to solve their own problems independently.

There is clearly no substitute for hearing from families firsthand how important these elements have been in their ability to experience achievements. Their enthusiasm in describing their achievements and the providers who had and were helping them reach their goals was contagious. The authors hope that this report captures even a small portion of that enthusiasm and reflects just how critical certain services and supports have been to the well-being of families.

ENDNOTES

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CHAPTER 1: INTRODUCTION

OVERVIEW

In systems of care dedicated to improving children's mental health, patterns of success have resisted direct analysis. The inputs into the systems have been clear enough—emotionally disturbed children and their parents, professionals of various disciplines, certain kinds of organizations and logistical arrangements, certain kinds of aid and treatment. The outputs are known as well—various degrees of resolution of the presenting problems, avoidance of more restrictive and expensive solutions. Nevertheless, what constitutes the what, the how, and the why of the inner workings of these systems have remained a kind of "black box," with the contents obscure and at times almost mysterious. The purpose of this study is to begin illuminating the interior of the black box, identifying the practices that connect the inputs with the desired outputs. In the process, it is hoped that the practices that seem to be working the best and the reasons they are working will be brought into the open.

What has emerged is a core set of characteristics, steps, or ingredients that appear to be present in all cases, regardless of the individual family or clinician. Evidently, those ingredients are activated in the relationship between the family and its clinician. As Burns, Hoagwood, and Mrazek have pointed out,

> *The effectiveness of services, no matter what they are, may hinge less on the particular type of service than on how, when, and why families or caregivers are engaged in the delivery of care. While traditional forms of care approached mental health treatment in a hierarchical top down approach (with the clinician maintaining some distance from the recipients of treatment), this approach is not reflected in newer forms of service delivery. It is becoming increasingly clear that family engagement is a key component not only of participation in care, but also in the effective implementation of it.*[1]

Families supported this position in conversations about successful interactions with systems of care. Parents had a narrower frame of reference and view of what constitutes success than might be expected. They tended to speak from the perspective of their child and their family, and they focused on concrete daily issues. In contrast, clinicians tended to have a broader frame of reference, including a sense of the strengths and challenges of each family and strategies for helping the family become more independent. Family members tended to place less emphasis on the formal characteristics of treatment options, such as a group home versus a hospital. Instead, they repeatedly focused on how services were delivered and by whom, rather than on any particular intervention.

Similarly, parents typically did not speak in abstract terms about interventions and insights. Rather, they made down-to-earth comments about caring, accessibility, and trust. They also spoke frequently about concrete achievements, such as improving school grades, reducing angry outbursts, making friends, and using specific coping strategies.

The role of clinician was less defined and was described without ironclad boundaries separating, for example, therapist from case manager. Clinicians who were seen as committed to a more traditional office-based approach and who appeared to feel uncomfortable providing services outside that setting were perceived as less effective. Those clinicians perceived to be most successful were comfortable defining their role independently of the setting in which services were provided and were willing to go into family homes. Descriptions of their work implied more flexible boundaries, designed to meet families where they are. The system itself placed a set of expectations on clinicians that involved flexibility in how they deliver clinical and therapeutic services.

In one way or another, the relationship between a family and its clinician and other support staff was characterized as the essential ingredient in all recipes for success. The relationship was not always sufficient to bring about desired changes without other services and supports—but the other services and supports were not sufficient without this basic ingredient. More specifically, the following points emerged concerning this relationship:

- Successful relationships were characterized by ease of access, depth of caring (a sense of genuineness and commitment), responsiveness, positive reinforcement, bonding and trust, a two-way partnership, and continuity of care. Successful therapists were seen as providing a sounding board, being supportive, offering unconditional acceptance, and validating the thoughts and actions of family members. Flexibility in terms of where and how therapy took place was highly regarded.
- Therapists regarded as successful tended to focus on the strengths of the child and the family and to proceed with encouragement and positive reinforcement. Through the emphasis on strengths, families spoke of receiving acceptance, respect, and support.
- Successful interactions were characterized by the family's participation at all levels, with the child having a voice and the parents having a sense of partnership.
- Successful interactions involved training and education for families and their children, which occurred as a succession of transactions in many forms as providers made their knowledge and experience available to the family.
- Finally, other aspects of services and supports repeatedly described as valuable included relationships between families and parent advocates, case aides, and other nonclinical program staff, as well as flexible funding, community-based services, priority for basic needs, and effective coordination of care.

It would be a mistake to conclude that these ingredients could be combined in a standard recipe to produce a given result every time. In families' stories of success, the combination of these characteristics appeared to be endlessly variable and nonlinear. There was no single good (or best) way of combining

ingredients, any more than there is one way to characterize good parenting. Nevertheless, relationship was always at the root of families' accounts of success. In these accounts, successful clinicians demonstrated the kind of treatment that Arnold and colleagues called for when they said,

> *Good clinical treatment is individualized, compatible with the clinician's style, intuitive as well as logical, and attentive to the affective relationship. Good science requires that the treatment be uniform, manualized, explicit, and logical, with the patient-client relationship a variable to be examined.*[ii]

In the end, it was the respondents who lighted the way into the black box of effective treatment in systems of care, providing a glimpse of the content and the context through their eyes. The remainder of this monograph reports more fully on those elements and illuminates a variety of recipes and a clear appreciation of the need for further study.

ORIENTATION TO THIS REPORT

Central to this study is the effort to give voice to successful families, allowing them to share their perspectives and experiences with other families who have similar needs and experiences, as well as with the professionals who seek to serve them. Following a review of the methodology and the literature, the monograph summarizes what families and their service providers have to say about the following issues:

- How success and successful outcomes are defined
- How supportive relationships are developed and, in conjunction with direct services, have contributed to their success
- How the structure and values implemented and embraced by systems of care serve as context and are an important foundation for service provision

The study presents definitions of success from several levels of providers, including CMHS technical assistance staff, grant community directors, clinicians, and other program staff caring for families directly. The profiles of the grant communities in Appendix A identify the features in each grant community that the technical assistance staff considered most promising. The providers' rationale in selecting successful families for the study is described in the Methodology under Site Selection.

Appendix B offers the perspectives of the two parent research assistants who participated in the study, beginning with study design and ending with analysis and reporting. They describe how they believe their contributions have benefited the study and how they have personally benefited from their involvement.

WHAT THE RESEARCH LITERATURE SAYS ABOUT SUCCESSFUL OUTCOMES AND FAMILY INVOLVEMENT IN SERVICE DELIVERY

Although the literature offers much information about families' perceptions of providers, the effectiveness of treatments or services, and the growing role of families in service delivery, it contains very little that describes success from the family perspective. Specifically, few if any studies have documented family definitions of success or have described what a family hopes to achieve throughout the course of receiving services. Although a review of the literature yielded substantial data on family perceptions of effective service delivery, no direct relationship was established between what families identify as desired outcomes and the service elements that contribute to those achievements.

Researchers in this study attempt to establish some connection between effective service delivery and positive outcomes, based on the assumption that effective services are more likely than ineffective services to produce positive outcomes. In the absence of data defining success and identifying services most important in a family's ability to achieve success, a review of the literature on service effectiveness emerged as the next best alternative. Consequently, this topic makes up a large portion of the literature review.

The main implication from the literature review is that family members can and do provide valuable insight and expertise in planning and implementing treatment options and service plans for their children. In addition, the literature offered insight into the qualities of successful family/provider relationships, an issue that families participating in the current research helped expand on.

PARENT INVOLVEMENT IN SERVICE DELIVERY

In recent years, the growing emphasis on having families play a more active role in the organizations providing services to children with severe emotional disturbances has led to questions about the appropriate level and nature of parent involvement. Despite legislative and policy requirements for increasing levels of parent involvement, parents and professionals continue to recognize the lack of wide-scale family input into the provision of care. In addition, there is insufficient research to encourage and guide professionals in the field to include parents and other significant caretakers in the design, delivery, and evaluation of the services being provided to their children. As research on the nature of effective parent involvement grows, those in the field are trying to understand the best way to get parents to participate successfully at all levels of their child's care.[iii]

As the discussion that follows reveals, the literature on parent involvement in services for children with severe emotional disturbances clusters around two main themes. The first refers to the parents' perceptions of effective service delivery. Specifically, it relates to the provider characteristics and qualities

that families see as being most important in a successful parent/provider relationship and to the program or service characteristics that families find most helpful. The second theme focuses on the development of parent and professional partnerships and discusses the challenges inherent in the process. It further focuses on the changes taking place in the field with respect to the parent/professional relationship and identifies some of the benefits of establishing this new parent/professional partnership service model.

DEFINING EFFECTIVE SERVICE DELIVERY

The following discussion of the literature suggests that both the direct relationship between parents and their provider and the parents' perception of their providers are important factors in effective service delivery. Most of the data address three main issues: the characteristics of parent/provider partnerships, of the provider as an individual, and of the program or service.

Characteristics of Effective Parent-Provider Partnerships

As the efforts to articulate the common elements of effective parent/professional collaborations grow in the field, a set of guidelines for identifying and potentially developing these partnerships is emerging. Researchers offer four characteristics for consideration: (1) Partnerships are built on the premise that all partners contribute specific skills and strengths to the relationship; (2) both partners voluntarily enter into a collaborative relationship; (3) partners are committed to honesty and trust within the relationship; they disclose any information relevant to the relationship and are committed to each other; and (4) all decision-making powers within the partnership are clearly assigned among the partners when it is formed.[iv]

In this same review, the authors describe communication between provider and parent as a critical factor in successful treatment interventions. Researchers specify the elements that facilitate effective communication and feedback between family and provider. They focus on the qualities of the individual professionals, including their personalities, and their actual behavior during and around the time of intervention.

Characteristics of the Provider

A review of several studies found that several qualities common to the individual professionals were the most helpful in service delivery and treatment.[v] One study of families in Wisconsin identifies the six characteristics of their service professionals that they considered most helpful: (1) knowledge in the field (as reflected in their understanding of issues related to early intervention); (2) good communication skills, including the ability both to explain information and concepts and to be an effective listener; (3) adoption of

a family-centered approach, as reflected in their ability to establish rapport and work effectively with both parents and children; (4) supportiveness to families; (5) possession of positive personality traits; and (6) a positive outlook.

This same review reports on another study in which parents identified supportiveness, sensitivity, and the providers' overall positive attitude as important characteristics. Eight professional abilities were also identified: (1) creating a supportive environment; (2) demonstrating a total commitment to the family; (3) establishing rapport with the family; (4) reinforcing positive aspects of the child; (5) demonstrating sensitivity to family issues; (6) sharing information and building parent's confidence; (7) clarifying team members' expectations; and (8) listening and responding to parents.

Other authors describe the relevance of parents' perceptions of their provider's personality and professional characteristics.[vi] Researchers have concluded that parents' views and opinions about the professional with whom they and their child worked determined their view about the program's overall quality and effectiveness. The implication is that parents' positive opinions about their child's provider often correspond with their belief that the services themselves are effective. In addition, when parents perceived their provider as helpful, they also believed that the provider had a high level of regard and concern for the child. This research also reinforces the belief held by others in the field that communication and feedback are essential in establishing positive relationships.

Open communication on the part of the provider was equated with helpfulness by the parents. Specifically, professionals who took the time to respond to parents' expressed desire for information on treatment alternatives for their child were considered to be the most helpful.

In another study, parents were interviewed concerning the specific qualities of professionals that they found most important.[vii] Effective counselors were identified as being understanding; having a sense of humor; and being down to earth, sincere, nonjudgmental, caring, and sensitive. Those professionals whose interpersonal interactions were rated positively were described as not being "stiff" or "formal" or like a "professional," but rather as being "casual," "informal," and "down to earth," like a "regular person." The implication is that parents seek a level of comfort with their providers. Therefore, establishing a positive connection with the parent, demonstrating respect, and refraining from being condescending are important tasks for the provider.

A follow-up study conducted in 1992 of 104 families with children who had been abused and children with behavioral problems yielded similar findings.[viii] Among the professional attributes found to be most valuable to family members were honesty and trustworthiness, the ability of the worker to establish a connection to the parents and children, and the ability to communicate a sense of support to the parents and

family. Parents in this particular study were less likely to recall "fancy therapeutic techniques" and more likely to recall the "dignity and respect received in treatment," as well as the general feelings of "validation and support."

A study of stepfamilies seeking counseling on issues associated with coping with their new family structures also rates similar qualities as important.[ix] In addition to their professional skill and level of expertise in stepfamily issues, the therapists' ability to communicate with warmth and trust was identified as being crucial. Like other studies, this research highlights the importance of effective communication and support as being the most helpful aspects overall. It also identifies a unique characteristic: the professionals' ability to validate families, especially at times when they may be less able to provide such validation for themselves.

The literature does not appear to support or favor parental acceptance of any one professional discipline over another. Rather, data vary from study to study, suggesting that parent perceptions of different service professionals (i.e., social worker, psychologist, etc.) are mixed. A review of several studies reveals that parents' opinions of professionals depend in part on professional discipline, yet there is no consistency in these findings across studies.[x] For example, to determine what, if any, impact a practitioner's mental models had on the parent/professional relationship, one study looked at psychiatrists, psychologists, and social workers.[xi] The results indicate that among the three groups, social workers were least likely to score well on the "family friendly" dimension, whereas psychiatrists were found to be the most supportive and least judgmental. Psychologists tended to score somewhere between the other two groups in most categories, while scoring higher on issues of open information sharing and the importance of research-based knowledge. In another study, the findings were reversed.[xii] Families reported the greatest satisfaction and the least alienation with psychologists, while reporting the least satisfaction and the greatest alienation with psychiatrists.

In a related area, both parents and professionals were found to associate the source of the child's behavior problems with the parent's attitude about the intervention and its effectiveness.[xiii] When parents attributed their child's behavioral difficulties to genetic or medical causes, environmentally based interventions were less likely to succeed. Conversely, parents who attributed their child's behavioral difficulties to environmental causes were found to be more likely to respond to behavioral or environmental interventions. Like others, this study found that generally, treatment methods that rely on a positive approach are more acceptable to families. Such treatments also tend to take less time and have fewer side effects. In addition, the more severe the presenting behavioral problems are, the greater is the likelihood that the family will accept a more intensive treatment or professional intervention.

Characteristics of the Program or Service

The literature also identifies the program characteristics that parents generally found most and least helpful. In highlighting the least helpful aspects of programs, some identify brief service availability and a lack of service intensity as two negative characteristics.[xiv,xv] Other literature focuses on the barriers that parents continue to encounter in securing effective intervention: a lack of funding for transportation and daycare; use of professional language that parents do not understand; and the daily time constraints experienced by many parents of children with severe emotional and behavioral disturbance.[16] Various articles mention the following as being the most helpful aspects of treatment or service:

- Setting specific treatment goals
- Requiring homework assignments
- Providing services for the entire family, not just the identified child
- Emphasizing the teaching components of treatment[xvii, xviii, xix, xx]

Other program characteristics identified in the research include the availability of therapists, such as the parent's access to a therapist's office and home phone numbers and the provision of in-home therapy.[xxi] It was, however, difficult to determine from the literature whether therapists engaged in these activities informally, without the approval of the agencies, or whether these activities had been deliberately incorporated into the service delivery approach.

DEVELOPING PARENT AND PROFESSIONAL PARTNERSHIPS

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DEVELOPING PARENT AND PROFESSIONAL PARTNERSHIPS

Challenges of Developing Parent-Professional Relationships

The literature suggests that it may be difficult for family members and professionals to become full partners in service delivery because of existing differences in perspective on several issues. Some researchers and theorists submit that the traditional therapeutic roles involve an unequal sharing of power between parents and professionals, a condition that stands in opposition to much of the current thinking on parent/professional partnerships.[xxii] There is some evidence that many professionals are still reluctant to abandon these roles, thereby risking the further alienation of the families they serve. The differences between parents and professionals appear to lie primarily in their focus. For example, in one study, professionals express concern over limited financial resources and personnel shortages in treatment settings, whereas parents stress staff training and quality services. In addition, parents emphasize their greater involvement in treatment activities and the removal of barriers to treatment, whereas some professionals "do not ascribe a major role to parent involvement." While parents focused on evaluations, which they felt were not usually extensive, professionals were more concerned that parents did not fully understand or accept their child's difficulty and therefore had limited involvement in the intervention.

Advances in the Parent-Professional Relationship

Notwithstanding the differences in focus between parents and professionals, data support the notion that a shift is occurring in the parent/professional role.[xxiii, xxiv, xxv] A growing number of parents have begun to establish greater equality in their relationship with service professionals. However, this shift is complicated by the strongly held opinions of many professionals either that parents are not seeking greater involvement or that their involvement is inappropriate. A study on the level of parent participation in services for children in hospital settings indicated that "many parents separate themselves from their children to develop greater normalcy at home."[xxvi]

The reported exception occurs when the child's problems are organic in nature. In those cases, parents were often more willing to learn about the child's illness. The authors referenced, however, caution that generalizing about parents' willingness to participate and partner with professionals is difficult because of the diversity in culture and context of family circumstances. For example, cultural differences influence the degree to which families share personal and confidential information, as well as their approach to dealing with physical and cognitive difficulties.

Despite these challenges, the literature reflects that both parents and professionals are taking on new and varied roles in caring for children with severe emotional and behavioral disturbances. For example, whereas professionals were previously considered the "expert" and parents simply the client, parents and primary caregivers are increasingly being viewed as experts because of their unique knowledge of their child's behavior. In response to these role shifts, professionals are being seen more as consultants with the primary responsibility to "stimulate changes in how people come together and interact within the problem solving process itself."[xxvii] The process of collaborative consultation has been described as "a model that actively involves educators, youths, and counselors as equal participants and experts in problem solving a specific issue."

In these evolving roles, parents and professionals appear to be working toward partnerships that involve shared power and accountability. One study describes six elements of successful collaborative relationships: (1) collaboration is voluntary; (2) collaboration requires equality among participants; (3) collaboration is based on mutual goals; (4) collaboration depends on shared responsibility for participation and decision making; (5) individuals who collaborate share their resources; and (6) individuals who collaborate share accountability for outcomes.[xxviii] In this context, the role of expert is not tied to a specific title or job description; rather, it depends on the specific nature of the problem and on those individuals who have relevant information.

In their new role as consultants, parents affect the course not only of their own treatment process and that of their child, but also of the broader field of treatment in general. By bringing new insights as well as expectations for more effective levels of care for their children and themselves, parents are beginning to have a broader impact on different types of therapeutic interventions. Consequently, new models of parent/professional partnerships are emerging as the roles of parent and professional continue to change.[xxix, xxx]

Benefits of Parent Involvement

A substantial amount of literature supports parent involvement in service delivery.[xxxi, xxxii] Increased parent involvement has been associated with many treatment benefits, including the ability of the service provider to more accurately predict parent behavior during the course of their child's treatment.

Increased parent involvement in service delivery has resulted not only in greater collaboration among professionals within disciplines, but also in collaboration between disciplines.[xxxiii, xxxiv] As parents are increasingly cast in the role of case coordinator for their child's care, medical, educational, and mental health professionals become more aware of the complex clinical issues faced by many families of children with severe emotional disturbance. Perhaps of greater significance, professionals become aware of the complexities inherent in parents' efforts to negotiate a complicated system of service delivery.

Parent involvement in a child's treatment has been associated with a corresponding increase in parent's feelings of self-efficacy—the belief that they can personally accomplish a given outcome because they possessed the required skills.[xxxv] An increased sense of self-efficacy corresponds with an increased investment in their child's treatment and treatment outcomes. Similarly, other research has indicated that improved parent self-esteem, which translates to more positive role modeling for children, has a positive impact on the intervention.[xxxvi, xxxvii]

Not only does increased parental involvement affect the individual family's treatment, but greater collaboration between parents and professionals has an impact on treatment systems generally.[xxxviii, xxxix] As professionals become involved with parents who engage in less traditional roles, they experience an increased awareness of and a willingness to explore treatment alternatives and shifts in their own roles. Ultimately, greater collaboration between professionals and parents and the formation of true partnerships allow an expanded array of interventions and available supports.

A second benefit of increased parent involvement in their child's treatment is reduced lengths of stay in the treatment environment.[xl] According to one study, a direct relationship exists between shorter stays in residential treatment services and increased parent involvement in treatment. This benefit is particularly valuable today because greater emphasis is being placed on the treatment benefits of maintaining children in their home environment and serious economic limitations create pressure for reducing the cost of treatment.

These same authors indicate that just as increased parent involvement results in more positive treatment outcomes, it also corresponds with an increase in positive feedback from parents about the program. As parent feedback becomes a more integral part of overall program design, program survival will likely be linked to increased parent involvement. Although the importance of parent involvement in service delivery has emerged over several decades and has manifested itself in legislation, policy, and, to a lesser extent, practice, continued research is required to substantiate the value of making parents more meaningful members of the service team. The dialogue between parents and professionals regarding the parents' role in the service system has begun and appears to be gaining significant momentum.

SUMMARY

Given the available literature, it is important for this study to give voice to families about the services and supports that are most influential in promoting their success. More specifically, researchers hope to supplement the existing literature with a clearer understanding of how families define success for their children and to establish a relationship between what families identify as desired outcomes and the service elements that contribute to those achievements. It is also hoped that this study will assist in developing a connection between effective service delivery and positive outcomes. The existing literature on service effectiveness helped inform the development of relevant interview questions, facilitating the further exploration of the importance of family involvement in service delivery and the inner workings of family/ provider relationships.

Study	Traits of Providers
Dinnebeil and Rule (1994)	• Have knowledge in the field • Have good communication skills—including listening and responding to parents • Adopt a family-centered approach • Support families and create a supportive environment • Possess positive personality traits—positive attitude and sensitivity • Demonstrate a total commitment to the family • Reinforce positive aspects of the child • Share information and build parent's confidence • Clarify team members' expectations
Tarico et al. (1989)	• Parents equate open communication with helpfulness. • Providers have a high level of regard and concern for the child. • Providers respond to parent's need for information on treatment alternatives. • Parents' perceptions of provider's personality and professional characteristics determine their view about the program's overall effectiveness.
Sells et al. (1996)	• Are understanding • Have a sense of humor • Are down to earth—casual, informal, like a regular person • Are sincere • Are nonjudgmental • Show caring and sensitivity
Coleman and Collins (1997)	• Are honest • Show trustworthiness • Have the ability to establish a connection • Communicate a sense of validation and support
Pasley et al. (1996)	• Professional skill and level of expertise • Ability to communicate warmth and trust • Effective communication and support • Ability to validate families
Study	**Traits of Collaborative Relationships**
Dinnebeil and Rule (1994)	• All partners contribute specific skills and strengths to the relationship. • Both partners voluntarily enter into the relationship. • Partners are committed to honesty and trust. • All decision-making powers are clearly assigned among the partners. • Communication between partners is critical.
Keys et al. (1998)	• Partners adopt new and varied roles in caring for children with severe emotional and behavioral disturbances (i.e., parent as "expert"). • Professionals act as consults with responsibility for stimulating change.
Friend and Cook (1997)	• Collaboration is voluntary. • Collaboration requires equity among participants. • Collaboration is based on mutual goals. • Collaboration depends on shared responsibility. • Collaborators share their resources. • Collaborators share accountability for outcomes. • Role of expert is not tied to title or job description.

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CHAPTER 2: METHODOLOGY

STUDY PURPOSE AND OBJECTIVES

The purpose of the study is to describe successful treatment outcomes and the services that promote them for children and families being served by a System of Care. It documents, from the perspective of parents of children with severe emotional disturbances, the services, approaches, and other program features that are most promising in terms of promoting family success. The study also places a special emphasis on understanding the features that constitute the "black box" of the successful therapeutic relationship. As comparison and validation, the study seeks to understand the clinician's perspective on these issues, as well.

The study relies on interviews with families and clinicians to answer the following questions:

- How are successful outcomes for children and families with severe emotional disturbances defined?
- What are the specific services or service responses that contribute to successful outcomes for children?
- What strategies are effective in engaging and maintaining families' involvement in services?
- What supports and relationships are most critical in promoting family success?
- What characterizes the successful therapeutic relationship and how does this relationship contribute to successful outcomes?

STUDY DESIGN

The fundamental premise in the literature—that families provide valuable insight and expertise in planning and implementing services—was incorporated into the overall design of the research. We included parents of children with severe emotional disturbance as partners in the research design with the expectation that they would ensure the relevancy of the study and make it more family friendly. By acting as "consultants" or "experts" and offering insight and knowledge, parents would enrich the research overall and possibly bring about unexpected benefits.

Along with the literature review, preliminary interviews with parent research assistants helped shape our initial thinking about the questions to include when interviewing families, providers, and key supports in each grant community. During the process of developing questions to address the research objectives, parent research assistants helped ensure that the questions were stated clearly and were family friendly. Interview and focus group guides were open-ended and semistructured, to allow and encourage participants to characterize successful outcomes from their own perspectives.

We deliberately designed the research to have a positive focus, aimed at providing answers to "what works." We therefore distinctly emphasized positive outcomes and relationships. In addition, we hoped to give families an opportunity to nullify or validate, and expand on, some of the findings from the literature as they relate to service effectiveness and family/provider relationships. Our ultimate goal was to learn and benefit from the experience of successful families and their service providers, so that other might benefit from their experience.

This research relies on a case study methodology, which allows researchers to consider the contextual conditions that may affect the issues being studied.[xli] The case study also relies on multiple sources of evidence to help triangulate, or support, the information the family reports. For this study, the primary care giver in each family served as the principal source of information about that family's experience. Other members of the family, such as the primary care givers' children, spouse, and parents, who were present during the interview with the primary care giver served as additional sources of information. In addition, some families identified key supports and gave permission for us to interview them separately. In most cases, families identified their multidisciplinary or multiagency team, therapists, or other program staff as their most important support. In our study, only a few primary caregivers identified someone outside the service system as their most important support. Given time and their availability, we interviewed these key supports, who included case managers, therapists, parent advocates, and other program staff, as well as extended family members and friends.

The Role of Parent Research Assistants

The participation of parent research assistants as part of the Florida Study Team was essential to the success of the study. Five parents of children with special needs participated in all aspects of the study, including design, data collection, analysis, and interpretation. These parents provided firsthand experience with the needs of children with serious emotional disturbance and their families, as well as successful outcomes.

Parent research assistants initially participated as interviewees for piloting the draft interview questions and subsequently worked with the team to clarify the study objectives and finalize the topic areas included in the interview guides. These parents played a central role in determining the final wording of the family recruitment flyer and the primary care giver interview guide, ensuring that these items were family friendly, focused on strengths, and were meaningful and relevant to families.

Parent research assistants were also part of the interview teams that traveled to the grant communities to collect data. They brought the parents' perspective to a two-person interview team, in which the other interviewer was a professional researcher. Across all grant communities, a parent research

assistant was absent from the interview only in two cases in Santa Barbara, where the primary care giver's primary language was Spanish. Because of limitations in time and funding, the team was unable to include a Spanish-speaking parent interviewer.

When the interviews were completed, parents worked in cooperation with their interview partner and the team as a whole to analyze the data and prepare written reports and charts to represent the findings for their individual grant community. Two of the five parent researchers also assisted in drafting certain portions of this monograph, specifically the section summarizing the families' hopes and dreams and the stories of their personal experiences with the study (see Appendix B).

Site Selection

We chose grant communities for the study to reflect a variety of contexts in which systems reform is occurring. We based our selection primarily on nominations from technical assistants representing three grant communities serving urban, rural, and small city/county populations. At the time we conducted our research, we organized, or clustered, grant communities with similar characteristics with the expectation that they would learn from one another and approach service delivery with some consistency, given the specific population they were charged with serving. As a result, grant communities serving the most densely populated areas represented one cluster, as did those serving smaller cities and suburban areas and those serving a rural population.

We asked technical assistants in these communities to nominate grant communities that they thought were implementing services or approaches at the practice level that held "promise" in terms of promoting successful outcomes for families. Beyond this request, we purposely kept the criteria undefined. By leaving the technical assistants to draw on their own definitions of successful outcomes to select these communities, they also contributed to the findings of the study. Technical assistants brought to their nominations several years of experience with the grant communities and a depth of knowledge based on their participation in meetings concerning service planning and implementation.

From the technical assistants' nominations and with the additional consideration of geographic representation, the research team selected at least one community to represent the rural, urban, and small/city county grant communities as a collective. After determining their availability, we chose the final five grant communities for the study: the North Dakota Partnerships located in Bismarck and Fargo, North Dakota (hereafter referred to as the Partnerships or North Dakota); the Multiagency Integrated System of Care in Santa Barbara, California (hereafter referred to as MISC); the Community Wraparound Initiative in the suburbs of Chicago, Illinois (hereafter referred to as CWI or Oak Park); the Southwest Detroit Community Mental Health Services, Inc., in Detroit, Michigan (hereafter referred to as Southwest Detroit

Mental Health); and the Guilford Initiative for Training and Treatment Services (hereafter referred to as GIFTTS), one of the four sites of the North Carolina FACES (Families and Communities Equal Success) System of Care State Level Project.

Once the research team identified the grant communities, we contacted Directors and Program Managers and asked them to recruit families for the study. We left the definition of a "successful family" open to interpretation by each grant community and requested that they describe their process and selection criteria. Given that the available literature on success is limited, the research team wanted to understand the factors that individuals at different levels of service provision take into account when defining success for the families they serve. Further research is required to document the factors that are most associated with family "success," including how to weight these factors to denote importance. In addition, further study is needed to identify and understand the factors that may have prevented a family from being nominated as successful.

Each community recruited six families to be interviewed. Since the North Dakota Partnership offered contact with two distinct service locations, one in Bismarck and one in Fargo, each location identified three families. Because of the number of families responding in Bismarck, a focus group was scheduled in that community, giving these families an opportunity to share their perspectives.

Using purposeful sampling techniques, families were stratified by their experience of success and by the richness of information they had to offer about the service and relationships most promising in promoting successful outcomes. Beyond this broad approach to sampling, each grant community employed its own unique method of recruiting families for participation in the study. Brief descriptions of their recruitment process follow.

The North Dakota Partnerships

Bismarck, North Dakota. The Project Director in Bismarck recruited families by posting in the family service center flyers designed by the research team. Families interested in speaking about their success contacted the program staff. Three families were scheduled to participate in individual interviews, with eight additional families volunteering for a focus group. An additional family provided its input through an informal interview, when the primary caregiver was unable to attend the focus group. These families represented eight of the 11 Care Coordinators employed in Bismarck.

Fargo, North Dakota. The Project Director in Fargo selected families on the basis of the diversity of their needs and the individual situations that they represented, including geographical considerations. The Care Coordinators were approached and asked to nominate families they believed had experienced some success. Three families agreed to share their stories.

Southwest Detroit Community Mental Health Services, Inc., Detroit, Michigan

Under the leadership of the Executive Director, the program supervisor of the Southwest Detroit Mental Health Services assumed the lead role in recruiting families for the study. Direct-care staff were told the goals, objectives, and parameters of the study and were asked to identify families they considered successful. Ultimately, families were identified on the basis of the staff's knowledge of their unique situations and outcomes. No specific definition or criteria of "successful families" was articulated, and staff members used their personal experiences and intimate knowledge of the families they serve to identify those who were functioning well. This result suggests that in Detroit, concrete or tangible characteristics of success may vary by family and may depend on each family's unique circumstances.

Guilford Initiative for Training and Treatment Services Site (GIFTTS), Greensboro, North Carolina

The Director of this grant community held the primary responsibility for coordinating family recruitment in Greensboro. An effort was made to represent the ethnic distribution of families served by GIFTTS. The determination of success was based on the service coordinators' experience and history with families, as well as on direct reports from families about their perceptions of their own success.

Multiagency Integrated System of Care (MISC), Santa Barbara, California

The MISC Program Manager, in consultation with individual caseworkers, selected families for the study. Caseworkers identified families they believed had achieved some level of success in the program and would be willing to share their thoughts with interviewers. Caseworkers used their depth of experience with families to identify children and families that were doing well. Discussions with the parents, family members, and school and therapeutic personnel contributed to the decision to include families in the study.

In the most basic sense, family "success" in Santa Barbara was defined as having met the treatment goals identified by the family and MISC personnel at the beginning of the treatment process. These goals included improved self-esteem and some change or improvement in home-based behavior, such as greater communication between parent and child or less hostile or violent behavior. Success was also defined by "precision of fit" data provided by the University of California, Santa Barbara, indicating improved school performance, both academic and behavioral.

Community Wra paround Initiative (CWI), Three Township Site, Oak Park, Illinois

The Clinical Director for Community Family Services (CFS), one of the three community mental health agencies that make up CWI, had primary responsibility for identifying families to participate in the study and relied on program staff providing direct services to make nominations. In making the final selection, the Clinical Director attempted to represent the geographical area of the Local Area Networks (LANs).

Family nominations were highly individualized, yet generally had the following characteristics: (1) families were functioning well; (2) the wraparound teams of the families nominated were strong, yet flexible, and had implemented a good plan; (3) families had demonstrated changes in the level of understanding of their children and families; and (4) families had implemented functional improvements. These families generally felt more supported, empowered, and in control of their lives because of services from CWI. In addition to these elements, the direct-care staff's perception of the "likability" of the families may have subjectively influenced the selection process.

DATA COLLECTION

Paired teams of interviewers collected data. In all but two interviews, one member of the pair was a parent research assistant. In those two cases, a Spanish speaker was needed to conduct the interviews, and no Spanish-speaking parent research assistant was available. Interviews in each grant community were completed over the course of one week in April through July 1999. A year later, the research team conducted follow-up telephone interviews with a small sample of families to expand on the successful therapeutic relationship.

The grant communities gave interviewers the names and contact information for all families and assisted in scheduling, identifying the location of the interviews, and providing the teams with directions. Prior to the teams' arrival at the site, those responsible for recruiting families obtained informed consent by using forms prepared by FMHI and approved by the Institutional Review Board of the University of South Florida. For Spanish-speaking families, all consent forms and other interview materials were translated into Spanish.

Families chose the location for the interview, with most selecting their own homes. All interviews were tape recorded with the families' permission to eliminate bias in the analysis and to provide detailed documentation and a reliable source for quotes about the families' experience.

DATA ANALYSIS

The research questions provided the foundation for summarizing and analyzing the data. This study collected data in the form of written notes completed by the research teams during the interviews, notes resulting from additional conversations both in the field and by telephone, and audio recordings of all interviews. The initial steps in data analysis occurred while the teams were still in the field. Each evening, the teams reviewed critical information from the interviews and other data gathered that day. Research teams representing each grant community reviewed their notes for clarity and completeness; reviewed the guiding research questions; and recorded their immediate impressions, ideas, and conclusions.

When they returned from the field, paired teams used the research questions to further analyze the data by identifying repeated themes and patterns and noting both consistencies and inconsistencies across families. Teams received analysis templates, or outlines, to help them focus on the themes and patterns emerging for each research question. Ultimately, these templates gave the researchers a practical framework to summarize the data and increased the uniformity across teams during their analysis. The templates also enriched the information by allowing additional themes that did not specifically speak to the research questions to emerge from each grant community. Where possible, data analysis examined the similarities and differences in family and provider perspectives. Field teams referred to their notes and audiotapes to extract quotes to reflect and support themes they identified and to give voice to the participants.

To enhance the reliability and validity of the data, the research team relied on a strategy suggested by scholars in the field of qualitative research.[xiii] A draft report was offered to the communities and selected research staff for them to identify factual errors, unfounded or unreasonable generalizations, and hypotheses. We asked the grant communities to review and verify factual data for their organization and to review the data as stakeholders. These reviews were helpful in ensuring the accuracy of the Grant Community Profiles (Appendix A) and the data collected through provider interviews. Although we did not allow grant communities to make direct changes to the interview-based data, this review allowed them to question or clarify references to ensure that the perspectives emerging from provider interviews were represented accurately.

On completion of the analysis for each of the five individual communities, the research team used a card-sort method to finalize the cross-site analysis. Each team completed note cards to organize by research question the major themes and patterns emerging from the data. We then placed the cards on a storyboard, and the entire research team worked to cluster and develop categories for both similar and dissimilar items. This process helped us understand the frequency with which common patterns in the data

emerged across grant communities. After completing the cross-site analysis, we convened a meeting with the research team and invited consultants. Over the course of this discussion, participants reached consensus about the most consistently repeated themes and patterns across communities.

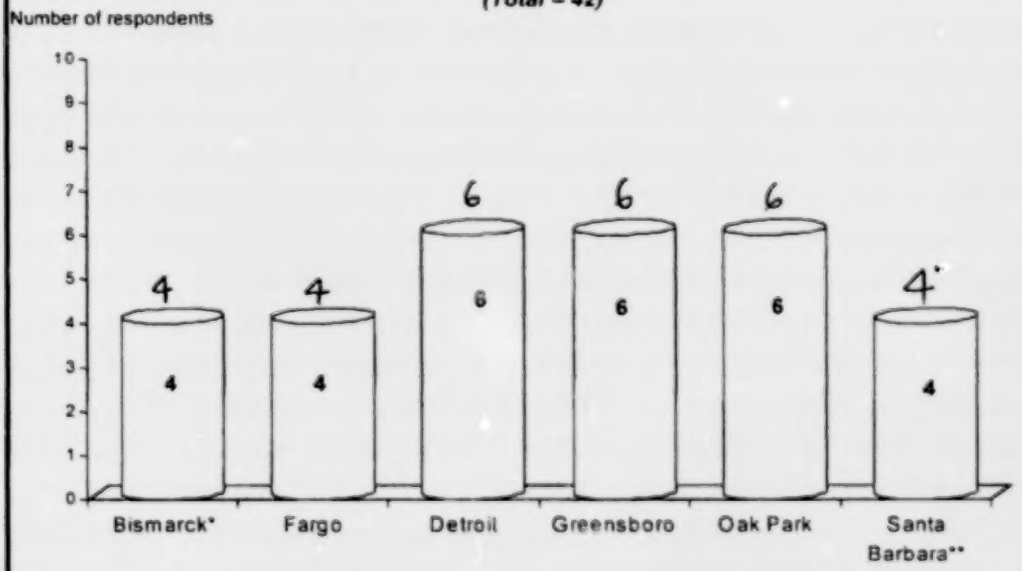
The monograph focuses primarily on the themes reflected by a majority of participants across communities. For the purpose of illustration, the discussion periodically refers to specific examples, which should not be interpreted as unique features of these communities. Although some unique features may be mentioned, they are not the focus of the discussion. In addition, although all grant communities adhere to a wraparound philosophy of service provision, not all apply this philosophy similarly. Specifically, some have implemented the model by using a more traditional wraparound team approach. This monograph makes no effort to determine the efficacy of one approach over another; rather, it explains what is most promising within the models as they are being applied.

CHAPTER 3: DESCRIPTION OF STUDY PARTICIPANTS

PROFILE OF PARTICIPATING FAMILIES

For this study, research teams interviewed 42 primary care givers (parents), 34 in face-to-face interviews and 8 in a focus group. These parents represented 41 children from the five grant communities. Exhibit 3-1 details the number of study participants from each grant community. Eighty-six percent (86%, n = 36) of the caregivers were female, while only fourteen percent (14%, n = 6) were male. The average age of caregivers was 40. With the exception of one "surrogate grandmother" in Detroit and an aunt in Greensboro, each caregiver interviewed was the child's biological mother or father.

EXHIBIT 3-1
Study Participants: Primary Caregivers
(Total = 42)*



*A focus group was also conducted with eight additional respondents, including seven individual primary care givers and one couple. **Includes four individual primary care givers and two couples.

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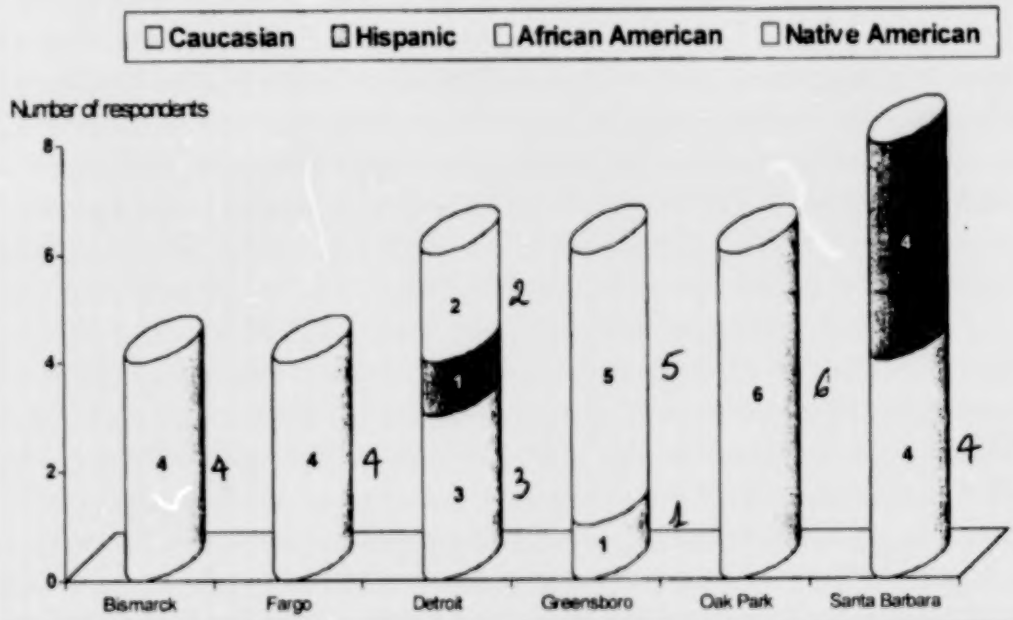
This sample approximates the custody status of children being served nationally across grant communities, where 76 percent of children are in the custody of either their biological mother or father, both biological parents, or one biological parent and a stepparent. The main difference is that 8 percent of children being served by the grant communities are in the custody of the state, 6 percent are in the custody of a grandparent, and 4 percent are with adoptive parents.[xliii]

The research teams interviewed parents of children who were receiving or had received services for an emotional or behavioral disorder in one of the selected System of Care communities. A few primary caregivers also identified individuals who had been important supports to their child or family and gave permission for them to participate in a brief interview about their relationship with the family. Most of these supports were program staff, with only a few being an informal (or nonpaid) support.

EXHIBIT 3-2

Ethnic Representation of Primary Caregivers Interviewed by Site

(Total = 34)



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Ethnic Representation

As depicted in Exhibit 3-2, the majority of the primary caregivers interviewed were Caucasian, (66%), followed by Hispanic (14%), African American (12%), and Native American (7%). The table also reveals the number of families of each ethnicity interviewed in each grant community. In Santa Barbara, two families identified Spanish as their primary language: as a result, those interviews were conducted in Spanish. All other interviews were conducted in English.

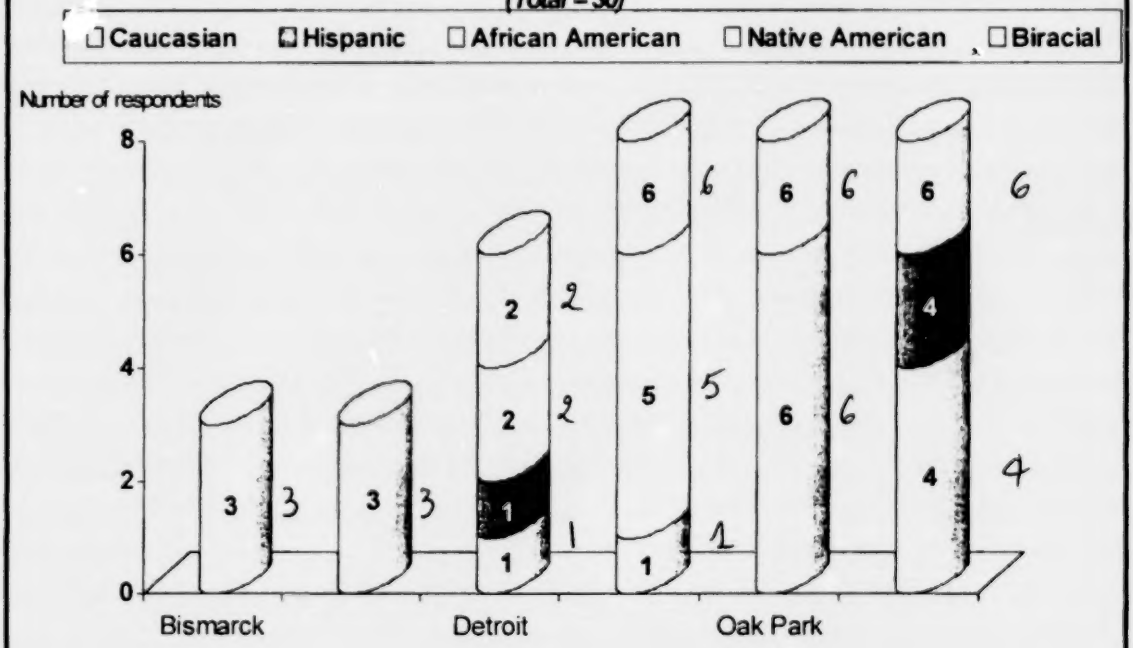
Exhibit 3-3 depicts the ethnic distribution of the subject children represented in each grant community. Although the majority (18) were Caucasian, 12 children represented a variety of minority populations, reflecting the diversity of families being served across System of Care grant communities. This breakdown also reflects the geographic location and service area of the grant communities studied.

The ethnic distribution of children in this study approximates the profile of children being served in systems of care nationally.[xliv] This sample is more heavily Caucasian (60% vs. 53%) and nearly equal in representing Hispanic children (10% vs. 9%). Although it includes fewer African-American (17% vs. 23%)

EXHIBIT 3-3

Ethnic Representation of Subject Children by Site

(Total = 30)



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and Native American (6% vs. 17%) children, an additional six percent of the children included in the study are biracial. Unlike the national sample, which includes a small percent of Asian children (<1%), this study included no Asian children.

Marital Status

Nearly half (47%) of the caregivers participating in interviews were married, while 53 percent were separated, divorced, or widowed or had never been married. The marital status of participants varied across grant communities. For example, none of the six caregivers interviewed in Detroit was married, whereas all but one of the families in Fargo and Bismarck had married care givers (Exhibit 3-4). Of the eight Bismarck focus group participants, five were married, two were divorced, and one was widowed. Marital status appears to differentiate this sample from the national profile of families being served in a System of Care by having a higher percentage of married couples. Although national demographic data do not provide information on marital status, the data indicate that only 33 percent of children were living in a home with two parents or caregivers.[xlv]

EXHIBIT 3-4

Marital Status of Primary Caregivers by Grant Community

Status	Bismarck	Fargo	Detroit	Greensboro	Oak Park	Santa Barbara	Total
Married	4	3	0	1	4	4*	16
Separated	0	0	1	0	0	0	1
Divorced	0	0	2	1	2	0	5
Widowed	0	0	2	1	0	0	3
Single	0	1	1	3	0	4	9
Total	4	4	6	6	6	8	34

*Two married couples

Employment

Nineteen (56%) of the 34 caregivers were employed either part-time or full-time. In Oak Park, all caregivers interviewed were employed, whereas none of the caregivers in Greensboro was employed (Exhibit 4-5). Although not represented in Exhibit 3-5, it is important to note that the Bismarck focus group had four participants who were employed full-time, three who were unemployed, and one who was employed part-time. Data were not available to compare this sample of primary care givers with those receiving services for their children nationally in systems of care.

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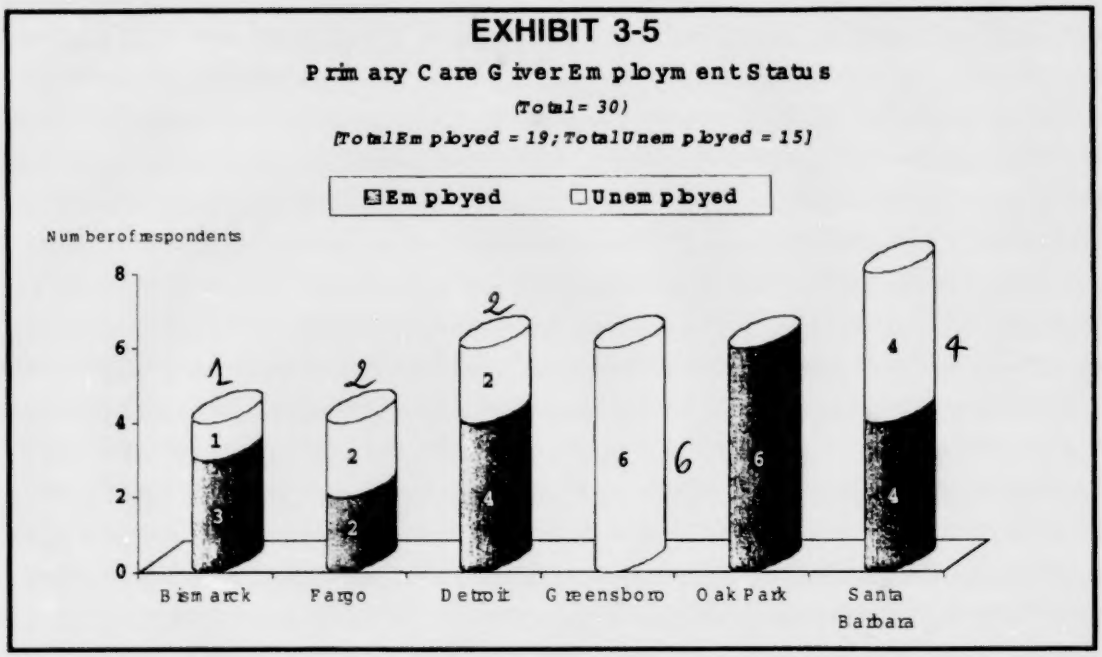
EXHIBIT 3-5



Age of Child

Corresponding with the national population of children being served in systems of care, the average age of the children in this study was 12. The youngest child was 6 and the oldest was 17.[xlvi] As shown in Exhibit 3-6, the children in Bismarck were on average younger than those in the other communities.

EXHIBIT 3-6

Age of Child

Age	Bismarck	Fargo	Detroit	Greensboro	Oak Park	Santa Barbara
Average Age	10	13	13	12	11	14
Age Ranges	7-15	7-15	8-17	7-14	6-17	8-16

Children's Special Education Status

Most of the children in the study were in special education. Twenty-five of the 34 children (74%) whose caregivers participated in face-to-face interviews were receiving some kind of special education services. This information was unavailable for Bismarck focus-group participants. As shown in Exhibit 3-7, all but one of the children from Santa Barbara and all of the children in Fargo were in special education. Detroit appeared to be the only grant community where most of the children were in regular classes.

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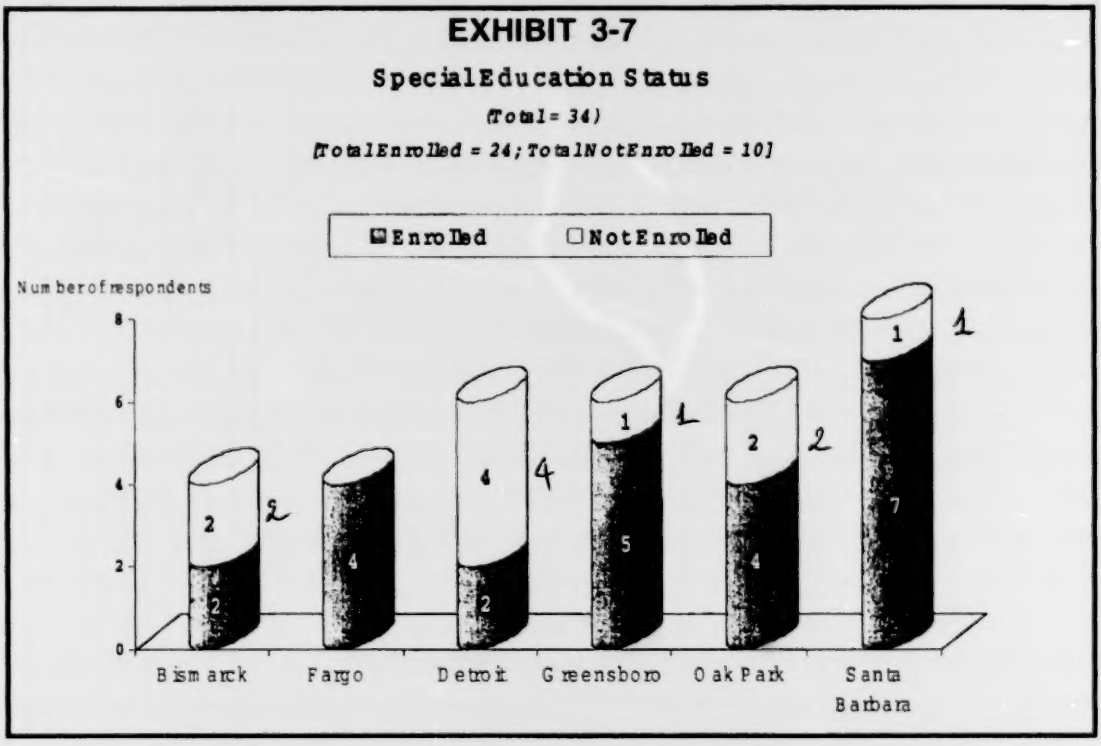
Although the majority of children in Santa Barbara were in special education, not all were receiving inclusion. In fact, several children had reduced their reliance on special education throughout the course of their involvement with MISC, moving to more regular classes and continuing only minimally with resource.



Repeated Grades

Although only 8 of 34 children (less than 25%) had repeated a grade (Exhibit 3-8), the proportion of those who had repeated a grade varied across grant communities. One-half of the children from Detroit and Greensboro had repeated grades. Data were not available to compare the children in this study with those receiving services nationally in systems of care.

EXHIBIT 3-8

Number of Children Who Repeated Grades

Repeated	Bismarck	Fargo	Detroit	Greensboro	Oak Park	Santa Barbara	Total
Yes	0	1	3	3	0	1	8
No	4	3	3	3	6	7	26
Total	4	4	6	6	6	8	34

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Age When Problem Was Recognized

The average age of the children when their emotional and behavioral problems were first recognized was nearly six (5.8 years). As Exhibit 3-9 illustrates, the problems were recognized as early as the first year for a child from Greensboro and as late as 16 years for one child in Santa Barbara.

EXHIBIT 3-9

Age of Child When Problem Was Recognized

Age	Bismarck	Fargo	Detroit	Greensboro	Oak Park	Santa Barbara
Average Age	5	5	7	6	6	6
Age Range	2-9	2-7	2-13	1-9	2-12	2-16

Person Who First Recognized the Problem

Primary care givers were typically the first to recognize that their child had a problem. Exhibit 3-10 indicates that 23 (of 34) caregivers initially recognized their children's problems. In these cases, either the biological mother or father was the first person to recognize the problem. In six cases, school personnel initially identified a problem; in five cases, it was either a physician or an extended-family member.

EXHIBIT 3-10

Person Who First Recognized the Problem

	Bismarck	Fargo	Detroit	Greensboro	Oak Park	Santa Barbara	Total
Mother/ Father	4	4	4	2	3	6	23
School	0	0	2	1	2	1	6
Physician/ Other	0	0	0	3	1	1	5
Total	4	4	6	6	6	8	34

Age of Child When Services Were Initially Received

The average age at which children first received services for their problem was nearly eight (7.5 years). As Exhibit 3-11 illustrates, the average age in each community ranged from six in Santa Barbara to nine in Detroit.

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EXHIBIT 3-11

Age When Child Began Receiving Services

Age	Bismarck	Fargo	Detroit	Greensboro	Oak Park	Santa Barbara
Average Age	7	8	9	7	8	6
Age Range	3-14	3-11	3-13	3-12	2-12	2-12

Child Diagnoses

All the children in the study had some emotional, learning, behavioral, or developmental disorder. Exhibit 3-12 identifies the predominant diagnoses for these children and their frequencies across grant communities, including the Bismarck focus group. Some of the children in the study had multiple diagnoses and more than half were diagnosed with Attention Deficit Hyperactivity Disorder/Attention Deficit Disorder. On average, slightly more than half of these participants were receiving medication.

EXHIBIT 3-12

Child Diagnoses

Diagnoses	Frequency
Attention Deficit Hyperactivity Disorder (ADHD)/Attention Deficit Disorder (ADD)	19
Learning Disability	7
Oppositional Defiance Disorder (ODD)	7
Other*	6
Depression	5
Obsessive Compulsive Disorder (OCD)	3
Hyperactivity	2
Emotional Handicap (EH)/Emotional Impairment (EI)I	2
Severe Emotional Disturbance (SED)/Anger Management	2
Autism	1
Being Tested	1

*Other includes self-mutilation, Pervasive Developmental Disorder (PDD), bi-polar disorder, femoral antiversion, Behavioral Disorder (BD), Cerebral Palsy (CP), mood disorder, and Asperger's syndrome.

PROFILE OF PARTICIPATING SERVICE PROVIDERS

The research team interviewed a variety of clinicians and program staff to obtain the provider's perspective for the study. Interviews were conducted with individuals providing clinical or direct services, such as therapists, case managers, care coordinators, clinical directors, and parent advocates. In addition, those who could provide an administrative perspective were interviewed, including directors and program managers of the grant communities. In all, 16 providers were interviewed.

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Most of these providers had been working as professionals in the field of children's mental health in some capacity for a minimum of 10 years. They reported holding a variety of positions throughout their years of service, including: social worker, special and regular education teacher, on-line service provider, clinical manager, administrator, pediatric faculty, program director, and therapist.

The length of time that providers had spent working in either their current positions or with the program in some capacity depended somewhat on how long that particular program had existed and ranged from a minimum of one year to a maximum of 13 years. They had also been living in or near the communities they served for various lengths of time. A few had been residents in the surrounding area for 29 years.

CHAPTER 4: WHAT IS "SUCCESS?" MAKING THE TERM OPERATIONAL

FAMILY HOPES AND DREAMS

One reason the black box of service provision is obscure is that emotional problems hinge on meanings, and meanings vary from place to place and from person to person. Therefore, identifying the practices that promise to make families successful required an understanding of what families meant when they used the word "success." To guide us, we asked the families to describe their hopes and dreams for their children's futures. Three themes consistently emerged that are related yet speak to different areas of a child's life:

- Behavioral improvements
- Improvement in school
- Living a productive, "normal" life

Many parents simply hoped that their children would "get better," referring primarily to the child's emotional, behavioral, or developmental problems and needs. They desired improvements in the child's ability to manage emotions and express anger constructively. Specifically, parents wanted their children to be less angry, less aggressive, and less destructive, toward themselves and others.

Improvements in school performance, including study habits, better grades, and fewer behavioral problems, were considered key predictors of a child's future. Parents underscored the importance of having their children complete high school and possibly attend trade school or enter the military. From their perspective, such achievements correlated with future employability and financial independence.

> *Graduation from high school. Being able to relate [to] and understand the rules and regulations, society-wise. (Parent)*

Parents also hoped that their children would become productive, well-functioning, accepted members of society. The hope that children would live "happy, normal" lives often included children being "good citizens"; obtaining gainful employment; and cultivating healthy social relationships with peers, other family members, and society as a whole. In some instances, "fitting in" meant looking like other children in the community in terms of similar clothing. In others, it referred to the absence of behaviors that separated the child from peers or community.

> *I am hopeful that my children will find their niches. I want them to use their strengths, manage their own behaviors, contribute to society, and find a place where they can shine. (Parent)*

I just want [child] to be happy...I want my son to have what he needs and what he deserves. (Parent)

I continue to keep the hope that he will live by himself by age 18 or 19. (Parent)

UNDERSTANDING SUCCESS

In sharing stories of success and describing the achievements of successful families, parents and providers helped the research team understand what constitutes positive outcomes. The goals or outcomes that indicated success for children generally mirrored families' hopes: school success, such as improved grades and behavior; better peer-to-peer and other relationships and interpersonal skills; increased ability to function independently; and the ability to manage emotions, especially anger and violent behavior. Successful children were described as making more "thoughtful choices"; realizing a need to talk to someone; taking initiative; and redirecting anger into a more positive expression, for example, by taking it out on a punching bag.

He's [child] been more optimistic in his life, in what he's done. It's also caused a positive situation in me too. (Parent)

Individual Achievements Versus Comprehensive Change

Though parents tended to agree with clinicians about what constitutes success, they were likely to define their success and that of their children by focusing on individual achievements. Clinicians had a more comprehensive perspective, considering each family's current situation as a whole. Parents and clinicians articulated similar markers of success, such as improved school performance and behavior and other functional improvements. Clinicians also spoke of indicators of systemic success, such as reductions in service utilization.

Achieving Goals and Meeting Basic Needs

Success was generally thought to have occurred when a child or family achieved the goals they and the clinician—or the wraparound team—had identified in the treatment plan (Exhibit 4-1). However, not all of those goals were likely to be "clinical" in the traditional sense. Many families defined success in terms of meeting the basic needs of the child and the family. "Basic needs" included medical, financial, and other requirements for adequate comfort and security in their daily lives.

According to clinicians, meeting these needs was necessary before families would have sufficient surplus energy and resources to address emotional and behavioral needs. They perceived meeting a family's basic needs to be a critical first step in the ability of family members to address the child's emotional

and behavioral problems, develop useful coping strategies and skills, and gain important insights into their child's behavior and their own. For that reason, basic needs were typically expressed in the goals of the treatment plan and represented markers of forward progress.

> *They asked us to come up with these [family goals]. This came out of us as a family, pretty much. The kids came up with a couple of these. A couple of them might have been that we had ideas of what we wanted to say and they helped us with them. (Parent)*

EXHIBIT 4-1

Sample of One Family's Treatment Goals

Less fighting
More bonding and politeness to each other
More loving, closer
Skills needed to get into adult world
Tolerance for differences
Problem-solving abilities
Thinking things through
Having more respect for each other's differences and opinions
Self-sufficient children with a strong [family] bond
Respectful children, appreciate each other for the good things

> *Some of the stuff I didn't even know I had a right to need. I just thought I was their mother, so it was identifying what I didn't even know I needed. (Parent)*

> *Having a common understanding of what they [the family] see as success. Then that really becomes the marker [for achievement]. (Clinician)*

Success in School

A reduced need for special education indicated school success, which was specifically defined as a child's ability to transition to mainstream classes or to demonstrate decreased need for other special education program offerings. Parents also referred to their own experiences as indicators of the child's improvement. Less time away from work and fewer calls from the school were tangible examples of how a child's ability to function in school improved the life of his or her parents and the family as a whole. For clinicians, a child's ability to stay in school and achieve better grades was also a predictor of improvement in other areas of life.

> *The program would like to see stability in the family; more effective parenting; improved school functioning. (Clinician)*

> *My child is going to school. She wasn't going to school last year and getting As. (Parent)*

> *They don't feel torn between their kid and their job. Maybe the school is managing the kid better ... but the parent's life is less disrupted. (Clinician)*

Interpersonal Relationships and Self-Esteem

Parents and clinicians perceived a child's ability to establish and maintain positive interpersonal relationships with adults and authority figures as an indicator of success and as evidence of improved self-esteem. Developing relationships and demonstrating an increased motivation to succeed in school, an interest in extracurricular activities, and better communication skills were all indicative of improved self-esteem. In the family setting, advances in self-esteem and communication translated into the child's ability to compromise and solve problems without fighting with parents or siblings.

> *We sort of learned how to negotiate and get along with each other on the wrap team. I think we're more well put together as a family. There's more cooperation, there's more compromise. There's not as much fighting, although there can be days. I think the problem solving has increased greatly. He [son] came through as a good compromiser. I think they've [children] both become more self-sufficient. (Parent)*

> *It changed his personality where he's a little bit more outgoing, especially with adults. He's a little bit more standoffish with kids, he has to work into it. (Parent)*

> *Through GIFTTS we are a family again. They helped us to bond closer together. (Parent)*

> *In the beginning, he [child] wasn't able to open himself up and at the end he was able to communicate how he felt and where he thought he needed to be and he is getting more self-motivated. (Parent)*

These children were also described as being able to "fit in" and feel like other "normal" children. Several parents indicated that their children were developing friendships for the first time with neighborhood children and schoolmates, extending invitations to play basketball or shop at the mall. Parents saw these children participate for the first time in extracurricular activities in their communities and enjoy themselves. Parents and clinicians agreed that as an outgrowth of feeling accepted and encouraged, children gained a sense of their own capabilities and strengths.

> *The parents see a future for the kid. The child's involvement [in activities] diminishes the view that they are such a problem. The perception is that they are more "normal." (Clinician)*

> *Feeling accepted is a big thing for kids. Not feeling that the whole world is against you. (Clinician)*

Independence

Clinicians repeatedly mentioned the importance of promoting family independence, especially in terms of the family's ability to negotiate various systems effectively. Mirroring the value of independence, families reported feeling more supported, empowered, and in control of their lives. Parents who regarded themselves as successful also spoke of changes in their level of understanding the children and the family's

unique dynamics. While they were experiencing increased independence, families also spoke of having greater stability. These families were more capable of establishing informal supports, which reduced their need for services.

> *It's a success when children are able to thrive at school and at home; when parents are able to use resources and advocate for themselves. (Clinician)*

> *What I would expect to accomplish is to truly find the proper match based on all the things that are hard to do as a system; values of the family culture, proper treatment match for that child's disability, that whole combination of things that makes this work. What I would expect is that the match be there and the progress be made and eventually the need for us be gone. (Clinician)*

> *The family is less stressed and managing the kids' behavior. They're less isolated and feel more supported, more capable. (Clinician)*

> *Prevention or return from out of home placement or hospitalization. (Clinician)*

CHAPTER 5: STRATEGIES THAT PROMISE SUCCESS FOR CHILDREN AND FAMILIES IN A SYSTEM OF CARE

Because this study seeks to understand positive inputs and outputs, the primary effort is to describe what works in the black box of a System of Care and how it works. What emerged from this study is that the practices most frequently associated with indicators of successful outcomes were in one way or another affected by qualities of the System of Care—and of the providers. For example, families frequently mentioned the attitudes and values of providers—in particular, caring, commitment, and dependability—along with clinical skill or a talent for innovation and change. For the purposes of this discussion, these practices have been grouped into three primary categories and their relevant subcategories:

- **Engagement**
  Meeting basic needs
  Parents as partners

- **Delivery of Clinical Services**
  The successful therapeutic relationship
  Individualized services
  Access and perceived depth of caring

  Collateral clinical services
  Medication
  Maintaining commitment to family goals

- **Structural and Operational Characteristics**
  Flexible funding
  Community-located services
  Continuity of care
  Advocacy
  Coordination of care
  Training and education
  Natural and community supports

Although this classification is a useful foundation for discussion, it is clearly not the only possible way to organize the findings. In fact, promising practices placed in one category could easily have been placed in another category. For example, the therapeutic relationship was guided and supported by the structural and operational values embraced by the system; meeting families' basic needs early in the process of engagement was made possible in part by the availability of flexible funding. Given the complexity of relationships among elements in the black box, reality is more complicated than this representation.

ENGAGEMENT

To engage in something means to be actively involved or committed; engagement refers to persuading or encouraging someone to participate or become committed. In this discussion, engagement constitutes the process by which the family and program staff develop and maintain a meaningful connection. It also refers to the process of developing conduits for communicating needs; strategic and operational information; and an array of attitudes and values, such as concern, compassion, respect, creativity, dedication, ethics, and trust. Engagement establishes the conditions under which all further interactions and transactions occur.

> *The parent advocate as part of the intake / assessment process [is] crucial to engagement. It immediately establishes a connection. Engagement of the parent is key. (Clinician)*

According to providers in this study, a central goal of direct services was to remove the stigma of pathology or abnormality from children with special needs, both with their peers and in the community. To meet this goal, they made every effort to "meet families where they are" by addressing each family's unique hierarchy of needs. In general, both families and providers perceived the availability of and access to an array of services to be more important than any single offering. However, they repeatedly mentioned certain service elements as being key to family success.

> *Even in the first meeting we could tell they were listening to what we had to say and I felt that they were involved, they were willing to put the time into it. So, I think after the first meeting, that initial negative feeling was starting to dissipate already. I would say that the first few months we started to see changes. (Parent)*

> *My relationship with the GIFTTS people has been very helpful. They were willing to provide assistance with family needs. They care about you individually. They have a goal to want you to get the things that you need to handle, handled. (Parent)*

> *Providing services to correspond with need I think maximizes the potential of the family and brings the family the kinds of resources they need. (Clinician)*

> *We have lots of services available. We have in-home intensive. We have big brother, big sister options all the way from volunteers to intensive higher trained folks that can do outpatient in a more creative way. (Clinician)*

Meeting Basic Needs

Although children were referred to the System of Care because of behavioral issues, providers recognized the importance of engaging families by addressing basic human needs at the stage of initial contact and assessment.[xlvi] Parents and providers portrayed families as coming to services desperate for help, having been unable to locate needed resources or having exhausted the resources available. It was therefore essential for clinicians and other care coordinators to listen closely and attend to what families considered to be their most pressing needs. They also stressed the importance of taking quick action to

address those needs, as a way to build trust and create a bond. Families perceived these early efforts as representing genuine caring and concern and a commitment to continuing support. Initial and continued responsiveness and a focus on family strengths also rekindled hope that help was available.

> *There were things I needed, to get everything going. They helped me get the services. One time I was laid off from a broken foot and we needed food in the fridge. They helped us find what we needed. They helped me understand how the kids did on tests and helped with an application for SSI disability benefits. (Parent)*

> *They are going to be bringing me over a food referral because I got off my food stamps. Friday they are going to hook me up with a ride to St. Vincent's to get some furniture. So they are really helping. (Parent)*

> *This program has been a godsend for our family. I am more pleased with this program than any program he [child] has ever been in. You ask for it and they pretty much do the best they can. (Parent)*

Both families and providers described the response of program staff to families' pressing issues as a critical opportunity to build trust and motivate the family to commit to participate in services. In this way, engagement constituted the beginning of the therapeutic relationship, one that allowed further intervention and eventual family success.

> *Provide all the support up front. Make their life easier...then you can get to the other issues. You can't get at those when there's chaos. (Clinician)*

> *Varying what you do with whatever that person needs. Really trusting that families know what they need. Staying more in tune with where they are, what works and doesn't and being able to shift it. (Clinician)*

> *Help was for the whole family. Food, making dentist appointments, transportation. (Parent)*

Parents as Partners

Both parents and providers perceived establishing a "partnership" with families in service provision to be a key element of success. From the point of initial contact and assessment, providers sought to empower families to take an active role in their own care. In addition to a strength-based approach to developing a comprehensive, family-focused treatment plan, providers emphasized outreach and attended to vulnerabilities. For these efforts to succeed, clinicians and other program staff had to know when to listen and when to provide information and explanations.

> *They listened first of all. They are in the home, you know what I mean? You can call them. You got an issue or depressed or stressed out about something, you can talk as long as you want, even an hour or two. Here is my home phone number. Call me at home. (Parent)*

A key point for me was I needed to feel like I was doing something. So, if they cut you out of the picture, I was not comfortable. I need to stay active in like the therapies and stuff. (Parent)

He'll [child] talk to them [program staff]. He'll give his opinion and he'll tell them what he thinks they should do for him now at times. So, he's starting to accept them as people that will listen and take into mind what he wants. (Parent)

Families stressed the importance of being involved in the treatment process and frequently described a working partnership with program staff. Supportive providers were described as listening to the concerns and opinions of parents and children and involving them in decision making when considering specific interventions. Through what families described as honest two-way communication, they developed a deep level of trust in their support network. They repeatedly expressed abiding confidence in the providers' level of caring for the well-being of all members of the family.

Everybody was honest. That was one thing we did too, is everybody had to be honest. Even if it was something that's not positive or you hate someone or whatever, we had to be honest. Be honest whether it was good or bad. (Parent)

I just think because she [facilitator] was always there, I mean she's always called... even now she keeps in touch. We haven't been in the wrap program for two years and we still have contact about every three or four months. (Parent)

I think the other thing that has helped is I've been involved on the committees and the development of the partnership project and that's been empowering. So building those relationships has helped. (Parent)

Services involving parents were described as much more far reaching than each intervening incident, because of the level of parental involvement. Parents reported gaining valuable skills in constructive problem solving. For example, family involvement in developing the goals and actions in their service plan seemed to foster a greater commitment on the part of both families and professionals to accomplish the agreed-on goals. Clinicians believed that involved parents demonstrated a greater willingness to examine difficult family issues and explore unfamiliar options. Involved families were described as being willing to try different things, participate fully in the wraparound process, and ask for the help they need.

I thought they were going to get up in my business and try to tell me what to do, but they helped me. (Parent)

We focused on where the families were with their child. We worked on earning their trust. Once you have done that, you have the family involved in all aspects. When the family is involved, you pull for each other's strengths. Honesty plays a key role in success. (Clinician)

Families who were comfortable communicating their ideas and expressing themselves were also perceived as having a better chance for success.

When I got into the program, it seemed to open my heart a little more, rather than me holding all my anger in. It's helped me to open up to people that I don't know. (Parent)

By working closely with their case managers and care coordinators, parents learned about their children's needs. Simultaneously, they absorbed the "culture" of the social service system and the schools, discovered their rights within those systems, and learned how to function effectively. Many parents perceived themselves as having become better advocates for their children and reported using their new skills most frequently in their interactions with the schools.

They have assisted me with my child educational-wise and made me more aware of the school system and the problems that an emotional child would have. (Parent)

It's helped me to open up to people that I don't really know." (Parent)

"I think when you have everybody at the table, I think there is a lot more ownership. (Clinician)

Families in crisis are often involved with five different agencies and those five different agencies are all kind of laying down the law about what the services are they have [to offer] and they are often at cross purposes and none of them take into consideration the overall family picture or what the other agency's impact on the family is. (Clinician)

DELIVERY OF CLINICAL SERVICES

Clinical services typically include those that require licensure or certification and that are aimed at direct change of behavior, thoughts, emotions, or the convergence of the three in relationships. In a system of mental health care, clinical services typically include medical and mental health assessment and (if indicated) treatment, psychopharmacology, and some form of individual or family therapy.

Within and beyond these services exist a range of clinical activities referred to in this report as collateral clinical services, such as crisis intervention and follow-up care, therapeutic foster care, drug and alcohol rehabilitation, respite care, and day hospitals. Depending on the situation and setting, they may also include occupational or physical therapy, diet and nutrition education, or other forms of intervention intended to bring about direct change. These services represent those mandated for grantees in the Center for Mental Health Services Request for Application, specifically, home based intensive case management, crisis management, respite care, and therapeutic foster care.

Nonclinical services may be anything that helps a child or a family, from providing transportation to helping make the living environment safer. Between these two are services that teach or train children and families to make plans, resolve disputes, be effective parents, reduce stress, or enhance any of the myriad aspects of living that affect the quality of life of child, family, and community.

It has become increasingly clear in recent decades that the interpersonal context in which clinical services are provided has an impact on their effectiveness. Mirroring those conclusions, this study confirmed that the "strength" of the relationship between provider and recipient affects the outcome of clinical interventions. Listening, attention, honesty, involvement, two-way communication, tangible help, availability, and authentic expressions of concern were key elements of successful therapeutic relationships. When these elements were present, children and parents formed trusting, lasting relationships with their clinicians.

> *They have to feel you really care about them. Attachment is not a one-way street; it's mutual. They have to feel that from you, really believe that you care about them and want what's best for them. (Clinician)*

> *You can never shame them. There always has to be a reason for their choices. You're job is to understand it, not to judge it. (Clinician)*

> *One of the keys has been complete honesty [with families]. Once people realized that we weren't saying there are no problems, we're all going to be happy and that strengths were a way to tie into strategies to address the problems, people kind of got, "Okay, I'm good." That's also helped with the relationship with families. (Clinician)*

The Successful Therapeutic Relationship

Although parents and clinicians regarded therapeutic services as essential to family success, they found it difficult to articulate or conceptualize when asked to shed light on the therapeutic process. However, since therapy played such a pivotal role in family success, the research team made every effort to understand what features or ingredients characterized these relationships. It was clear that beginning with the initial contact, the trust developed between families and their therapist(s) set the tone for their involvement and commitment to services. Parents and children also relied on their therapists to listen, help find solutions for problems, guide families through crises, and facilitate continued growth.

> *Her [counselor's] approach is to do family counseling. She has been really helpful in giving us the tools we need and the understanding we need to appropriately set limits and boundaries, to love unconditionally. So that's probably, I think, the biggest help. (Parent)*

> *It's the unspoken. It's how you listen, how in tune you are with them, how much attention you pay, how willing you are to invest in the things they're interested in. (Clinician)*

Therapists and counselors were frequently described as having an approach that offered flexible boundaries, positive expectations, and an emphasis on collaboration. At the core of these services was a commitment to meeting the needs of the individual, with the therapist using a variety of interventions and approaches designed to speak to the abilities, interests, and needs of each child and family. A commitment on the part of therapists to flexibility in terms of their role and the appropriate setting for service delivery characterized their interactions with children and families.

They were able to provide assistance with family meetings. They help you individually. They have a goal to want you to be able to get happy. (Parent)

They praise me when they see me doing something and they like pick me up. (Parent)

With [son] it was the role playing that built trust. [Child] took charge of sessions and told the therapist what he wanted to do. (Parent)

You might say [to the child], "I think about you and take you with me. You need to learn to do that too." Kids need to learn to take it [therapy] outside the office. (Clinician)

Although titles and responsibilities varied slightly by grant community, individuals in the roles of therapist, case manager, care coordinator, case aide, mentor, and parent advocate were among those most frequently mentioned as providing key support (Exhibit 5-1). However, parents often struggled to identify staff by title or discipline, typically referring to them by their first names and as their "helpers." A blurring of the boundaries of "traditional" family/clinician relationships characterized these relationships. Families described these supportive individuals not as belonging to categories of professionals but as being most like close friends and "family."

EXHIBIT 5-1

Key Family Supports

Wraparound or service team
Therapist or counselor
Parent advocates (often called resource coordinator, family resource developer, care coordinator)
Natural and community supports

I mean I adore her [counselor]. On Christmas vacation, wherever she goes, she will call and I think that somebody that takes the time to call from out of town to see how he's [son] doing, it means a whole lot. (Parent)

Here it's almost like family. They [members of the team] talk to each other all the time. (Parent)

Parents and providers described relationships in which a conventional top-down approach was abandoned for a partnership developed to implement change. Parents and children considered themselves full partners in this process, working cooperatively with clinicians and program staff to identify needs, articulate goals, and share in the tasks required to achieve those goals. At the same time, clinicians relieved parents of some of the stress and burden of addressing the problem alone and served as a resource for information, skill building, and personal insights. Here again, both parents and providers perceived the level of family involvement to be predictive of the likelihood that the family would experience successful outcomes.

I believe we have the answers to a lot of our issues.... We have answers within ourselves and I'm just kind of a facilitator. I'm someone to help sort out... I'm not the answer man. People come in and they have their hand out, like I have the answer. I'm like, "No, you have the answer. And if I can help you understand that you have the answer, then you can take ownership"... and then change can last as opposed to being a temporary change. (Clinician)

Individualized Services

Clinicians who were deemed successful focused on what the family identified as its needs, rather than on a fixed repertory of available services. Parents, in turn, characterized the therapeutic relationship as involving mutual respect, a focus on the strengths of child and family, and the clinician's ability to clarify and prioritize goals.

She [wrap team facilitator] would do everything. I wouldn't have to do anything, but show up [for the wrap meeting]. She would bring desserts. She would do everything. She took all the notes and gave me copies. It was just really nice to sit back and have people help. It was just wonderful. (Parent)

Being able to go with the flow with whatever the pressing need was at the time. Everybody starts to feel like you're on their side and they can get their needs met. (Clinician)

When I work with this child and this family, nothing is wasted. And if I'm doing what I need to be doing, nothing is lacking. (Clinician)

Several parents who initially feared becoming involved reported that their fears were quickly alleviated and replaced with a sense of relief that someone was listening and offering help. According to families who had experience in other kinds of service systems, the individualized approach set these System of Care communities apart from other programs. They described atmospheres of respect and understanding and a sense that what these programs offered was entirely different from what they had encountered when seeking help in the past.

She [care coordinator] started by asking us what we needed to help us. We didn't know, but we had run out of steam. (Parent)

I did not expect too much. I thought it was something set up by the court and that they were going to monitor things. I didn't realize that they were going to have such family involvement. And actually the more people you get to know here, it is like building the community to look after the kids again. (Parent)

Bonding appeared to grow with repeated interactions in a variety of circumstances, as clinicians and other supports addressed the family's needs during crises and assisted them with both practical and highly personal or emotional issues.

She [wrap team facilitator] was fantastic! She would have stuck her neck out for whatever we needed. (Parent)

The kid did not really have any friends, so I served as a sounding board. Someone who unconditionally accepted him...for who he was...new kid on the block, having to make friends, understanding the difficulties with that. (Clinician)

If they're bonded, they really like to see their therapist. He [child] doesn't want to take a break from his therapist. Whenever [therapist] is sick and calls, it really upsets [child]. (Parent)

They [program staff] are there to support you, respect you, know that you know your child the best, and you don't give up. (Parent)

Access and Perceived Depth of Caring

The most promising ingredients of family/provider relationships were those most difficult to quantify. They included nearly unlimited access of parents and children to their providers, the perception on the part of parents that providers cared deeply for both child and family, and evidence that providers were highly responsive, demonstrated by persistence and creativity in meeting the family's needs. The staff's availability and prompt response to needs, combined with a strategy of positive reinforcement, were frequently identified as an indication of their depth of caring and a key to family success.

If it's a coordinator in the family or a teacher or whoever, I think the relationship which brings trust keeps the family coming to the table. (Clinician)

I think it's been extremely important too for the provider to become aware of how important family perspective is and getting feedback from the entire family and the providers using that information to look at how well they are providing services to families. (Clinician)

When he [son] realized that what he said meant something, that's when he got engaged, he wanted to be involved. (Parent)

Access to clinical and support staff had a major impact on the perception that the support was helpful and focused on family success. Parents repeatedly praised clinicians and support staff for responding readily, whatever the need was and whenever the need arose. They estimated the typical response time to telephone calls to be approximately 30 minutes. In addition, support staff routinely called on the weekends and holidays just to check in. In some cases, parents were given pager numbers for crisis situations. One mother reported that after calling 911 when her daughter attempted suicide, she paged her parent advocate, who came to her home, transported her to the hospital, and remained with her through the night until the daughter had stabilized.

Every time I need something or needed to go somewhere, she [provider] had the time. She would take me. (Parent)

I can call her whenever I need her [Care Coordinator]. She is resourceful and supportive. She is the communicator between us and the school. (Parent)

If he [son] has a crisis and he pages somebody here [at the center], they answer him. (Parent)

We have a contract agency in the county that does intensive family preservation. That has made a huge difference. With that kind of 24-hour, seven-day-a-week coverage, you can really keep families together in the homes. (Clinician)

It's just been very helpful to have somebody there that you can just pick up the phone and if they are in their office or leave a message and they will call you right back. You can try to explain the problem you're having and they will go through it with you and say, go do this, or I'll come over and I'll help you. (Parent)

As suggested in the literature, families equated depth of caring with genuine concern and support, mutual trust, and responsiveness.[xlviii] In addition, clinicians and other support staff were often credited with having the individual qualities necessary to develop meaningful and productive relationships with families. They were described as "unique individuals" and "special people," who were both respectful of and attentive to the entire family and its situation.

Real people. Real people to work with. Their concern and their availability. (Parent)

Probably the biggest thing for me was that the people in the relationship were very...even keel. I grew up in a very up and down household and I'm not that bad, but I tend to up and down a little and for me to see kind of a stable, easy going, even keel kind of person that doesn't have these crazy mood swings...that was sort of a calming factor to me. (Parent)

To be an effective Resource Coordinator/advocate, you have to have a certain kind of personality to be able to partner with families and really hold true to the wraparound philosophy...strengthening parents and allowing parents to be heard and...to drive the system. (Parent)

The people I deal with, they are loving people. They are caring people. (Parent)

She [counselor] is the person who has been there for us and that makes such a difference in a counselor, not only to have the academic knowledge, but to have those experiences, where she can totally relate. She has been unconditionally there for us. (Parent)

Collateral Clinical Services

In addition to individual and family therapy, programs used collateral clinical services, depending on each family's individual need. With the wide array of services available, we recognized that further study would be required to be more fully illuminate the contents of the black box with regard to the specific clinical services that seem most likely to promote success. As we indicated earlier, however, the ingredients would likely include crisis intervention/emergent services, therapeutic foster care, intensive case management, drug and alcohol services, respite care, and day hospitals. No clear trends emerged in terms of which services were most effective in promoting family success. Rather, successful clinicians and treatment teams used

these services as part of an individualized approach, addressing both the immediate and long-term needs of each family. In addition, families were much less likely to emphasize these services, despite their importance to the families' successes.

> *More intensively in the past five years we expanded our continuum of services for children to include not only outpatient therapy and screening for psychiatric hospitalization, but a fuller continuum. This includes an early intervention and prevention program, evaluation and outpatient treatment, home-based clinical work, intensive assertive community treatment programs, respite, crisis residential and hospitalization, and family counseling. (Parent)*

> *We have a child stabilization unit, which is really a child and family stabilization unit, so that when families are in crisis, whether it's a placement crisis or a psychiatric crisis or substance crisis, we can bring the family into our unit and do some very intensive family work with the whole team. We can bring the community in. We can do brief network intervention and work on planning for the next crisis and how the community can respond. (Clinician)*

> *I tell them [crisis counselors] I am about ready to throw something at somebody and they say, "Don't do that. Let's talk about it." They calm me down and they get on the line with the kids even and say would you please go to your room or something like that. The kids are now starting to talk more about their problems. (Parent)*

> *He [child] receives home-based therapy. He has his GED classes. He meets with a person from BABCO, which is drug prevention. He currently has a mentor. (Parent)*

> *We have mentors, intensive home therapy. We have safe beds, which are like crisis beds, a place where kids can go for up to 96 hours. (Clinician)*

> *Respite has helped just to give you a break and kind of step back from it and not be so involved in the therapies. It's nice to see some of their [respite staff] reactions with [child]. That has been positive. They kept facing the fun side of [child], so we in turn can kind of relax and see the fun side. (Parent)*

Medication

In many cases, appropriately prescribed and managed psychotropic medication proved essential in moderating problematic emotions and behaviors, thereby giving therapy and other interventions a chance to work. For parents whose children had proved difficult to diagnose and treat pharmacologically, assistance and support throughout this process were particularly meaningful. They reported feeling somewhat helpless when faced with medication management, and they needed information and assistance to deal with undesirable side effects and to communicate with psychiatrists and other physicians.

In many of the case histories, the appropriate use of medication in combination with therapy appeared to render children's behavior more manageable, both in the home and in school. In particular, children who had been diagnosed with attention deficit hyperactivity disorder (ADHD) were described as showing improvement in their ability to listen and focus. Which increased their capacity for emotional and relational development.

> *It [medication] is often an important tool in getting kids and families to where they want to be. (Clinician)*
>
> *With the Welbutrin, he [child] is doing a lot better. (Parent)*
>
> *Roughly 35% of the children are on medication, so medication education [was a key intervention]. (Clinician)*
>
> *It's a useful tool overall, but it's not for every kid. ADHD kids benefit from meds. It modifies the behavior, so you can reach them. (Clinician)*
>
> *It keeps him settled down for the time in school. He comes down off the meds in the evening and becomes aggressive. (Parent)*
>
> *For major depression and psychotic disorders, as well as the attention deficit disorder, medication is very important, coupled with appropriate therapy. (Clinician)*

Maintaining a Commitment to Family Goals

Child and family improvement and an ongoing need for help and support were most frequently mentioned by parents as reasons for continuing with services. The motivation to continue working on identified goals was attributed to families' having their needs met and perceiving that the children were happier and healthier. Strong bonds with clinicians and program staff and a high level of trust also appeared to translate to a deep sense of satisfaction for both parents and children.

> *Just the determination to want to make things better. I didn't feel comfortable with the way things had been going and the relationship between me and the kids. I wanted them to have a little easier transition from childhood to adulthood. (Parent)*
>
> *He [child] has changed to much... he's not as emotionally disturbed. He is a happy boy now. (Parent)*
>
> *They were empathetic about things that would happen in the family. I felt like the whole team was involved in making sure my family was... you know, made it... like we were an improved product. I just felt like they were personally invested. Even though they aren't part of our family, they had just as much desire to see us become a better and healthier family. (Parent)*

Successful families were motivated to continue in services after reporting reductions in stress, renewed hope for their child's future, an overall improvement in family relationships, and a sense of empowerment. Of great importance to parents was their increased understanding of the "normal"

developmental process and their child's emotional and behavioral problems. This knowledge better equipped them to deal with crises and to meet their child's needs. Parents reported that developing skills in parenting gave them the tools to manage their child's behavior and to resolve conflicts. Clearest of all measures of success was the ability to prevent out-of-home placement and avoid more restrictive levels of care.

> *Prevent the child from needing more restrictive levels of care or other dramatic change, such as a new school placement. (Clinician)*
>
> *We were learning the signs of what kind of day he was going to have, depending on what kind of morning he had. (Parent)*
>
> *They kind of helped me understand [son's] problem. He's hyperactive. (Parent)*
>
> *The one [child] that's diagnosed bipolar, he was on his way to a group home and having that support system, it's made it possible to keep him at home...so far. (Parent)*
>
> *This [program] is what keeps children in our home and not in a group home situation. (Parent)*

Parents and clinicians described children as benefiting from continued involvement in services, a conclusion based primarily on positive changes in behavior. They depicted children as making gains in impulse control, anger management, and the ability to recognize the onset of symptoms, all of which improved their ability to cope with their emotions. Children became less destructive in the home and less likely to act out in school.

> *They [siblings] haven't tried to kill each other in six months. They're learning anger management through their counselor. Now they go to their room or go out for a walk to calm down. (Parent)*
>
> *My son now sleeps through the night. He used to have to have someone walk down the hall at night to do to the bathroom. The counselor asked him about his fears. It was one of his goals to complete. (Parent)*
>
> *She [child] was able to identify the first clues of cycling up [toward mania]; the moment at which she needs medical evaluation, to check herself into the day hospital, take medication, etc. She recognized the differences between her behavior, which was taken to the extreme and other children's similar behavior. (Clinician)*
>
> *[Child] is dramatically improved. He gets along better, even with kids with similar problems. He sees in them what's going on with him (Parent)*

STRUCTURAL AND OPERATIONAL CHARACTERISTICS

Both directly and indirectly, parents and providers pointed to the delivery system for services as affecting the quality of the services received. These references spoke to the organizational and operational structures of the system, the approaches they offered, and the values and principles that guided service

provision. Together, they constituted the context within which successful service provision took place. This context dictated the when, the where, and the how of service provision, with an emphasis on the following priorities:

- Flexible funding
- Community-located services
- Continuity of care
- Advocacy
- Coordination of care
- Training and education
- Natural and community supports

Flexible Funding

The availability of flexible funding allowed providers to be innovative in their efforts to integrate children and their families into the community and to consider nontraditional interventions (Exhibit 5-2). Funds were used to purchase sports equipment and bus passes, pay camp fees, and pay for alternative activities for children. Flexible funding also helped meet the physical, emotional, intellectual, and social needs of families, paying for nutritional counseling and behavioral reward programs, for example. In some cases, the funds helped relieve families of the financial burden or the emotional stress that comes with being the sole provider for their children. When needed, programs assisted parents in providing clothing; securing low-cost childcare for preschool children; and purchasing school supplies, books, and other necessities.

EXHIBIT 5-2

Use of Flexible Funding in North Dakota

Flexible funding paid for gasoline so that a father could drive out of state to see his wife and son, who had to leave home temporarily to receive medical services for the son.

A family with two children with special needs was provided transportation to an alternative school where the children were assisted both academically and behaviorally.

They helped us one year with getting books for the kids' school through the flex funds that they had. And some clothes a couple of times. They would give us school supplies that people had donated. They'd put our name on the Santa thing that they do at Christmas. (Parent)

The other thing that has been really helpful for him is that they got him a membership at the Boys and Girls Club so that he can be with some kids his own age that have positive attitudes, rather than let's hang out on the streets. (Parent)

We don't have a formal transportation system, but we do have some money set aside that we can assist families with transportation. (Clinician)

She [nutritionist] comes over every two weeks and sets goals. You can have so many starches, etc. We try to go by that and so when I am making dinner I am looking at a balanced meal. (Clinician)

An example of the ingenuity allowed by flexible funding comes from North Dakota, where one family had difficulty motivating their child to attend school. Every morning, the family engaged in a long and frustrating battle with the child, who refused to get dressed or complete any other preparations for attending school. After struggling for hours, the family was sometimes forced to take the child to school in pajamas. For the parents, this severe burden interfered with their work commitments and strained their emotional well-being. In response, the center assigned a case aide to take over the task of getting the child to school every morning. The parents were thereby relieved of the burden and could concentrate on their other responsibilities.

I can call [care coordinator] whenever I need her. She is resourceful and supportive. She is the communicator between us and the school. (Parent)

Community-Located Services

To parents and providers, successful programs were committed to engaging with families in contexts the families saw as meaningful and relevant. They offered a variety of home-based interventions, including therapy, case management, crisis intervention, respite care, tutoring, and mentoring. Providers described home-based treatment as the norm, with traditional office-based services becoming increasingly less common. Parents spoke positively of this effort, indicating their ease of access to therapists, the settings in which therapy was conducted, and the frequent presence of program staff in many aspects of their daily lives.

The fact that they [therapist] take him away from the house and he's not in an office where he has to sit still is very helpful for [child]. (Parent)

Continuity of Care

Although some grant communities provided a "single point of contact" (i.e., a single provider with primary responsibility for the family) throughout the course of services, all communities introduced families to a primary contact during the process of engagement. Where possible, this contact remained part of the family's service team. Programs using a wraparound or service-team approach established a family's trust with one or two individuals and then introduced the family to the other members of the team. Regardless of the specific process, the critical nature of the initial contact was clear. It appeared to correspond with the family's future involvement in services and the level of trust they would develop with clinicians and other program staff. As a result, it had great bearing on the degree to which therapeutic relationships would be

successful. Whenever possible, programs involved a parent advocate in early meetings; this involvement was based on the perception that shared experience has a positive impact on establishing a trusting relationship.

> *Care coordinators establish that trust, because they are the single point of contact and help the family navigate through all the services, regardless of the agency. (Clinician)*

> *We have a wonderful psychologist right now and he is really doing a lot of work with us a family unit. He sees the children one-on-one every other week and my husband and I go in and tell him what our concerns are and about these problems that are continuously arising. (Parent)*

Continuity of care seemed to correspond with the level of family involvement in services and the formation of supportive relationships. Families valued the relationships they created with providers. The longer the relationship lasted, the more mutual trust appeared to have developed. When staff did leave, families experienced some sense of starting over with the replacements, yet few families said that they felt that the full momentum of their forward movement had been lost. Generally speaking, new relationships were successfully formed in the same context as the original bonds, and parents seemed willing to accept new staff because of their overall positive experiences with the system.

> *Contact over-time helps build rapport. Care coordinators are not licensed and their training varies by contract agency, but they provide consistent contact and availability. (Clinician)*

> *Having that care coordinator in place was very supportive and being able to have somebody come in and get him a few times a week with those school issues, so I didn't have to deal with it on top of the mental health issues. (Parent)*

> *Having that extra person [care coordinator] support you, respect you, knowing that you know your child best...you don't give up. (Parent)*

Advocacy

Crucial to family success was the presence of program staff in the schools and other community settings and service systems. In these settings, staff served as advocates for parents and their children. Advocacy was especially important for families in North Dakota, who perceived that the community stigmatized them because of the presence of mental illness or a child with problems. To relieve the sense of alienation experienced by these families, the Partnership located Care Coordinators in the schools to serve as mentors to the children and liaisons with the school staff. Similarly, in other grant communities, parent advocacy was believed to be helpful in bridging gaps and cementing family ties to the community.

Parents spoke of forming bonds with parent advocates (e.g., Resource Coordinator, Family Resource Developer, Care Coordinator), because these providers shared the experience of being the parent of a child with special needs. Many parents said that these staff members offered a greater depth of

understanding. Parent advocates offered nonjudgmental emotional support during crises, helped with problem solving, assisted families in understanding and navigating the service system, and served as advocates in other service agencies. Staff members in this role were described as fostering productive, long-lasting relationships with the families they served. Consistent with the findings of other studies, the high quality of the communications between families and parent advocates was often at the core of what made these relationships influential.[xlix]

> *The [Parent Advocate] has helped me with a lot of the problems that have come up 'cause I can call her at anytime. Sometimes, as you know, just having someone to talk to just helps to talk through some of the problems. (Parent)*

> *One of the families you'll meet today [to interview] has a child with autism. And the Family Resource Developer on that team also has a child with autism. And that was just the perfect match...where that made all the difference for that parent. (Clinician)*

> *She [Resource Coordinator] went through the same thing it seems like that I have been going through. She knows how to calm me down. She won't let me go until she knows I am calm. If I say "Yes," she says "I know there's something still bugging you. What is wrong?" Every once in a while we go out for lunch, just to get away from everybody. We sit there and talk about what we are going to do at the next wrap meeting. (Parent)*

Coordination of Care

Families regarded case management and coordination of care as being the most meaningful and helpful direct services. Through these efforts, programs advocated for children and families in the schools, in the communities, and with other service agencies (Exhibit 5-3). Coordinated care also ensured that families had a single point of contact across services and systems, which promoted continuity of care. This was especially true in Santa Barbara, where providers portrayed the relationship between the family and the care coordinator as a critical connection with the agency, one that increased the likelihood of the family's continued involvement in services.

EXHIBIT 5-3

Example of Coordinated Care

One mother in reported receiving the following help from the GIFTTS program:
Transportation and attendance at IEP meetings
Employment assistance for her husband
Enrollment of her son in driver education class
Advocacy for her son with the football coach
Financial assistance and Christmas gifts

The facilitator kept talking to me, trying to tell me how it would work. The bottom line of why we decided to go for it is because she was going to be the liaison person with the schools and we thought, well it would help to have that person. We could bring anyone we wanted to [to team meetings], anyone we felt comfortable with and wanted there. We never felt the need to have anyone else there. (Parent)

Coordinated care extended beyond agencies devoted to providing mental health services. Other agencies included the schools, the juvenile justice system, and providers of a great variety of other services. These efforts were credited with reducing out-of-home placements, improving overall family stability, and creating more effective support networks than one or two mental health service providers could offer alone.

The MISC program in Santa Barbara facilitated collaboration by co-locating with referral sources and providers from other systems (Exhibit 5-4). Having multiple systems and providers in one building improved communication and cooperation among organizations, to the benefit of the families they served.

EXHIBIT 5-4

MISC Co-Located Service Systems and Agencies:
Child Protective Services
Probation
Mental Health
Public Health
Drug and Alcohol Treatment
Child Abuse Prevention

Training and Education

Providers regarded parent training and education as promising tools in creating a stable home environment. Through training and skill building, parents gained an understanding of their children's emotional and behavioral problems and learned effective parenting techniques. This belief was supported by parents, who reported feeling empowered to be better advocates for their children and more capable of meeting their children's needs overall. To the families, involvement in treatment planning and progress reviews represented a particularly important opportunity for gaining new skills in setting goals and tracking achievements. Parents indicated that they carried these processes and skills beyond the service system, using them in daily life to identify, work toward, and achieve goals on the job and in interpersonal relationships.

By talking to people, if I don't understand something, they [program staff] can help me understand what it means and what I should do about it. (Parent)

We do training and education for families and team members. We have provided some of the training through the partnership project, but we have also made funds available for families and other team members to attend training that is real specific to individual kids. (Clinician)

[Program staff] turned me on to these meetings about schizophrenia. It's helping me keep him on track and encourage him and understand more about his illness. (Parent)

I was learning how to discipline more consistently. The wrap team kind of encouraged me, you know, "Stick to what you're saying." So, they kind of encouraged me to stick up to the kids a little more. They [wraparound team] gave me permission to go back and say [to children], "Hey, I made a mistake [with discipline]" and helped me with that. (Parent)

When we go in there, he [counselor] helps us problem solve to find positive ways to help the children, when they're acting out violently. He teaches us ways that we can redirect that behavior and let them know that it's not an acceptable way to react to their problems. He's given us all sorts of little ideas, positive reinforcers, working on goals, and stuff like this. (Parent)

Natural and Community Supports

Providers placed a special emphasis on developing natural and community supports, with families reaping the benefit of involving extended family in the service process and establishing supports in their communities. Families indicated that they were encouraged to become involved in the community, especially in terms of encouraging their children to participate in extracurricular activities. They saw these activities as being instrumental in helping "normalize" children and improve their self-esteem. Specific activities included summer camp, basketball, a bicycle project (i.e., putting bikes together and going on biking trips), and a junior lifeguard program.

Having the opportunity to be involved with the federation for families [helped with success]. Five years ago, I went to the first convention. That changed my life. At that point I had given up. I really felt that I was the only one going through this. So, going through that and being able to hear other peoples' stories and the empowerment. That really gave me hope. It gave me the knowledge to know what to ask for and how to ask for it. (Parent)

Beyond the service system, a few families had important natural and community supports, including extended family and church youth workers. One mother of a child with autism reported that several members of her extended family participated on the wraparound team and worked tirelessly for the good of her son and the family as a whole. Another mentioned an uncle as a critical support. Probation officers and special education teachers represented an extended support system in some cases, and church pastors and teachers spent time listening to parents and offered genuine caring to the entire family.

They know how to intertwine with other family members, knowing that I am not the only person that is having problems. Just being introduced to other family members and having the support groups. (Parent)

CHAPTER 6: CONCLUSIONS

This study, which focused on successful outcomes, afforded families an opportunity to make their voices heard. Given that opportunity, families shared their hopes and goals and identified what it was about the services they had received that helped them reach their goals and fulfill their hopes. Their accounts illustrate the presence of an array of promising practices, described in the previous chapter. These services had been provided in the context of systems of care for children suffering emotional disturbances. Thus, information about what worked for them also brought to light what makes systems of care successful—illuminating what has until now been something of a "black box."

The promising practices inside the black box of the systems of care were less notable as techniques than as occasions for the affirmation of certain values and attitudes. These values and attitudes allowed providers to engage with families respectfully and honestly, recognizing that the success of their interventions hinged on information only the families themselves could provide. Successful providers addressed the family's perception of needs and of what constituted success in meeting those needs. Partnership with the families entailed their empowerment, but it ultimately empowered the providers as well.

The families' definition of success contained the following elements:

- Basic needs and other goals were met.
- The child experienced individual achievements.
- Indicators of school success were present.
- The child's self-esteem and interpersonal relationships with adults, particularly authority figures, improved.
- The child began to fit in with other children
- The family gained the ability to solve problems independently.

Families continued to value clinical services, which remained essential to accomplishing family and program goals. However, these services were said to have the most promise of success when boundaries and status and role differences between clinician and client/patient were relaxed. Providing clinical services in nontraditional settings, such as the family's home, was favorably regarded, as was the willingness of the clinician to expand his or her interests to include actions traditionally reserved for case managers and advocates.

If attitudes and values seemed to drive the promising practices, certain structural characteristics of the systems of care made them possible. These included the availability of flexible funding, a noncategorical approach to service provision, openness to interdisciplinary services, and a focus on aiding the whole family to become a growth-enhancing environment for the child.

Providers emphasized the importance of delivering services that

- addressed the needs of the entire family;
- were offered in response to the individual needs of each child and family;
- relied on the resources of the community and promoted the development of natural supports; and
- involved families as full partners in the service delivery process.

These factors, of course, are fundamental precepts of systems of care. Providers and parents spoke directly or indirectly to three of the principles of systems of care: services must be child- and family-centered, individualized, and community-based.

ENGAGEMENT

The strategies the grant communities used during engagement proved successful in maintaining active contact with the families, especially when compared with programs that have struggled to retain children and families in treatment and report a high rate of attrition. The focus on practical needs, such as securing safe housing, clothing, and school books, was based on the recognition that when families are concerned about practical issues, their ability to deal with their children's disabilities is often diminished. Families reported that when they received assistance with the issues that were causing them immediate stress, frustration, or fear, their sense of confidence in the provider grew quickly. Early in the engagement process, providers typically made efforts to involve families as full partners and to help them understand the "culture" of the agency and the larger system. Parents saw these initial interactions as setting the tone for the quality of the relationships between families and providers that would form over the course of services.

The close bonds formed between providers and families represent another very promising feature in promoting successful family outcomes. Not only the quality of these relationships but also the type of support that families received from the relationships were felt by all concerned to contribute to their success. Families reported having almost unlimited access to providers, who supported them during crises, assisted with problem solving and decision making, and acted as liaisons with schools and other community agencies.

These relationships generally began during the engagement process, when providers proved to be responsive, able to formulate and address problems, and focused on the strengths of the child and family. Families often characterized their key supports as being the first people to "really listen." They were also

credited with caring about the well-being of the child and family with a depth nearly equal to that of the parents. The families' key supports were also extremely persistent and creative in meeting needs. One family captured the perceptions of many in saying,

> *They never give up. I am just astounded by the many creative ways they keep coming up with to help him. Often times they don't understand him, but they never give up. At one point I had to ask myself, Are these people for real? Is it that they just need a job or something, or... they must really love their job. I can't believe how genuine and real they really are. (Parent)*

Most striking was how frequently providers were described as being "like family" or friends, implying that the traditional boundaries between service provider and recipient were becoming blurred. Families closely bonded with their providers as individuals and were frequently unable to identify them by their position (i.e., therapist, case manager, resource coordinator). Instead, they referred to them by name.

The promising features of family/provider relationships were reported consistently across communities, regardless of whether the key support was a specific individual or the entire wraparound team. It was clear from families that these bonds were important in improving families' sense of self-worth. They also helped ensure continuity of care and fulfillment of the systems' guiding principles. Even after leaving (i.e., graduating), the program, some families continued to have contact with their key supports and were confident that should they need anything, program staff would welcome their call.

CLINICAL SERVICES

The most promising clinical services were family and individual therapy, medication, skill building, and crisis counseling. The relationship between family and therapist set the tone for the effectiveness of services. These relationships were characterized by mutual effort and a focus on family empowerment. Clinicians were committed to an individualized approach and used an eclectic array of services to meet families' needs. Individual and family therapy was also defined by the system's values, which emphasized flexible roles and settings for service provision. Providers were effective in delivering services in a manner consistent with the system's foundational beliefs, with an emphasis on functional change rather than on clinical outcomes.

The systems' efforts to enhance families' skills and to promote functional improvements also played an important role in family success. Skill building began with identifying family needs and strengths. Families used this information to improve their parenting skills and felt more capable of caring for their children. They were better able to solve problems both in and outside the home, balance employment and household responsibilities, and handle crises constructively. Ultimately, improved parenting and life skills resulted in better self-confidence and an ability to effectively deal with life issues and events.

For some children, medication was a key to their well-being and therefore was an important component of their individualized service plan. Unfortunately, managing a child's medication was often a long and frustrating experience for parents, involving many trials of medications that either did not produce the desired results or produced unwanted side effects. When medication was managed effectively, families reported that their children were more able to participate in school, interact with their peers, and handle day-to-day life.

Children who responded well to medication often made bigger and more lasting emotional and behavioral improvements. For example, parents reported that when their children were receiving the appropriate medication, they were better able to handle their emotions, were less angry, and were less likely to act out violently. Medication helped some children sit still and concentrate, which improved their school performance and their ability to focus on problem resolution.

The fact that clinical services were mentioned less frequently by parents as contributing to successful outcomes should not be perceived negatively. Despite the importance of medication in moderating behavior, once medication was successful, it tended to fade into the background. However, when prompted, parents readily acknowledged the role of medication in behavioral improvements, by increasing the child's ability to concentrate or to be free of depression or anxiety, for example.

STRUCTURAL AND OPERATIONAL CHARACTERISTICS

The additional, or nontraditional, supports, such as flexible funding, family nutritional counseling, financial planning, and individualized respite services, were also very promising in promoting family success. Families and providers consistently mentioned flexible funding as being important in strengthening the connection between the child and the community. Funds were spent on items that would facilitate children's involvement in extracurricular activities, including team sports and camps. Some grant communities implemented a reward system that allowed children to earn points and purchase such items as trendy clothes, toys, and sports equipment. These items reportedly helped give children a sense of fitting in with their peers. Parents and providers credited these unique interventions with helping to "normalize" their children, both among their peers and in the community. They were successful not only in promoting positive peer-to-peer relationships, but also in improving children's interactions with authority figures.

Families also perceived providers as having expertise in furnishing or locating other services that are generally considered to be outside the scope of traditional service provision. As an example, grant communities often used respite services to meet the unique needs of families. In some cases, respite services allowed parents to reconnect as a couple or to give attention to their other children. Respite care was used during crises to provide immediate intervention for the child with special needs. It was also used

in other unique family circumstances, such as intervening with a child who refused to go to school so that the parents could go to work and be there on time. These supports not only increased families' sense of hope and confidence in the provider, but also empowered them to help themselves.

Time spent planning and problem solving with families was found to be a clear opportunity for them to learn and build skills that they could take beyond the service system into their homes and communities. Family involvement in this context is not part of traditional service delivery, nor is it clearly articulated in the System of Care terminology. Family involvement at this level extends beyond the original notion of "full participation" and has become a learning process that promotes the development of applied skills. These skills include the ability to think through problems, identify tasks to solve a problem, make decisions, and effectively communicate with others concerning both problems and successes. Within this learning process was a clear focus on what strengths the families were bringing to the table and what strengths they could use when confronting new challenges.

A Paradox for Further Investigation

Providers also indicated a need for children and families to be prepared for change. Therapists developed this readiness by providing information, teaching skills, and promoting personal and family insight. Through role-play and modeling, for example, providers might teach families to resolve conflicts or teach new skills for parenting. Therapists also focused on educating parents and their children in new ways to think about the specific emotional and behavioral problems with which they were struggling.

This last point raised the issue of what some providers referred to as "therapeutic readiness."

> *Many of these children are socially or developmentally delayed. Therapy relies on the skills that not all kids have or will ever reach. Some can reflect on their experience and their internal experience. If they can't identify those and articulate them, therapy doesn't work. Then you look for other things to help them. Maybe it's respite, where you can offer on the spot crisis intervention, etc. We're generally less successful with these kids and sometimes we don't know what to do, but it's not their fault. (Clinician)*

On the surface, these comments appear to conflict with the kind of open, nonmanipulative approach usually regarded by parents as promising. In addition, the need to acculturate the recipients into the subculture of the therapist before they can benefit from therapy appears conventional. The scope of this research did not enable us to investigate this paradox, although further study would lead to a deeper understanding of promising practices and further illuminate the black box.

IMPLICATIONS

Enterprises as complex and extensive as systems of care will always retain something of the black box about them. Nevertheless, it is imperative that attempts to understand what is in the box and what takes place there continue. Families and providers contribute important insight into some of the most promising practices at the level of service delivery. Although our interviews were informative and meaningful, there are limitations to what we can and should infer from such a small number of interviews with a small group of families and providers. In addition, our study did not compare our interviewees with successful families from non-System of Care providers or with unsuccessful families from either service system. Although we identified several critical elements of successful family/provider relationships are identified, we can offer no instructions for selecting and training staff capable of forming these bonds. Despite these limitations, the consistency across grant communities is striking and lends credence and credibility to the findings.

Across grant communities and regardless of geographic location and other factors, including socioeconomic status, our findings about the system elements that promote success were consistent. In the grant communities studied, "success" seemed to occur in the following circumstances:

- Families were fully engaged in services.
- Providers listened carefully and respectfully to families' priorities and addressed the highest priorities first and promptly.
- Services addressed the needs of the entire family.
- Services were designed on the basis of the families' identified strengths and needs, as well as their criteria for success.
- Services promoted and strengthened the connection between family and community.
- Providers, both individuals and teams, demonstrated genuine caring and were persistent and creative in meeting families' needs. Most important, they were fully accessible to families, often 24 hours a day, seven days a week.
- Services were flexible and provided additional supports not typically found in the rational approaches to service provision.
- Services provided opportunities for family empowerment, learning, and skill building. Through this process, families were given the chance to solve their own problems independently.

Family readiness also appears to have a bearing on success, as does the readiness of their communities. Children and families who do well in systems of care may share circumstances, strengths, or supports that contribute to their ability to get their needs met or to achieve the goals of treatment. These assets may include family stability, such as a two-parent home, stable employment, or community supports. The availability of early intervention services, which allows emotional and behavioral problems to be identified early, may also be a key factor in promoting success. Drawing these conclusions, however,

requires further study, including gathering data to reflect a broader perspective on success from a more diverse sample of children and families. This new study should include families who are not doing well in systems of care and families being served outside the system.

If this study provides any lesson, it should be this: Understanding the processes by which children with emotional disturbances and their families are made whole will be possible only through a reliance on the hard-won wisdom of the families who have undergone the difficulties directly and have been seasoned by their experiences. The usefulness of this information supports the value of this in-depth approach to examining parent perspectives and appeals to the field of children's mental health to listen. As one author comments,

> *We should recognize the importance of research and evaluation that trace backward from the experiences, behavior, perceptions, and status of service recipients.*[h]

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APPENDIX A: GRANT COMMUNITY PROFILES

THE NORTH DAKOTA PARTNERSHIP

Bismarck, North Dakota

Bismarck, the capital of North Dakota, is a small community of 60,000 to 70,000 people in the middle of the state. It is bordered by the Missouri River on the west and sits above the Sioux Reservation on the south. The majority of residents in Bismarck are descended from Swedish, German, and Irish immigrants who came to this part of the country in the mid to late 1800s to farm the rich, fertile soil of the Missouri River Valley. North Dakota natives proudly make the distinction between farming and ranching, and let visitors know that their farms produce much of the country's wheat, sugar beets, and other crops. The courage and spirit of their heritage have resulted in a culture that is proud, with strong family bonds and commitment to neighbors.

The population in the counties surrounding Bismarck is spread over a large geographical area in many small towns. Each town has its own school district; thus, most schools are small, and specialized programs are scarce. Many families derive their income from farming, employment with state government or manufacturing. Salaries are low; for example, beginning teachers earn $18,000 annually. Bismarck has two colleges: the University of Saint Mary and Bismarck State College.

The climate is severe. It is not rare to have winter days with subzero temperatures and heavy snows, which result in spring flooding. These factors may contribute to a sense of isolation for many residents. Concerns about alcohol abuse and traffic accidents have led to a crackdown on drivers leaving bars, according to residents of Bismarck.

The small city/county technical assistant nominated the North Dakota Partnership (including both Bismarck and Fargo) for the Promising Practices Study because of its incorporation of wraparound services and its focus on individualized services. The Partnership prides itself on starting "where families are" within their cultural reality and on developing relationships that lead to better outcomes. Families are involved at all levels of service delivery, including planning for their own care, participating in committees in the community, negotiating contracts, and hiring staff. Because of this involvement, providers have become more aware of the family perspective and, consequently, have been able to deliver better services. These services are

strength-based and may include care coordination, mentors, respite services, flexible funding, safe beds, and intensive in-home care. The staff has seen little turnover among the Care Coordinators, which has provided consistency for families.

Referrals can be made by parents, guardians, or professionals involved with children who have emotional or behavioral difficulties. These children must demonstrate the most complex needs and are at risk for being removed from their home. A child must meet five criteria to participate in the Partnership:

- Be under age 20
- Be diagnosed with an emotional, behavioral, or mental disorder
- Be placed out of home or at risk for placement out of home or has a GAF of 50 or below
- Need service in two or more community agencies such as mental health, substance abuse, education, juvenile justice, or child welfare
- Expect to have the disorder for a year or more

Fargo, North Dakota—Region V Partnership

Fargo is a small community of 80,000, located in the eastern end of North Dakota in the Red River Valley. The majority of residents in Fargo are of Swedish, German, and Irish descent, whose ancestors were attracted by the rich, fertile soil and shipping routes for agriculture and goods from the north. In the summer, the landscape is a beautiful mosaic of wheat, corn, potatoes, beans, sunflowers, and sugar beets. The farms are quite expansive; the average Valley farm has more than 2,000 acres. North Dakota ranks high as a producer of crops, which has led to prosperity for some of the more successful farmers. But like Bismarck, Fargo has harsh winters.

The population has become more diverse as the community has grown over the years. Along with three universities, Fargo boasts of shopping centers, restaurants, and hotels, which are a major draw for North Dakotans living in rural communities. These businesses employ many young adults, who come to find work opportunities after completing school. Manufacturing plants for agricultural supplies and equipment further support the economy.

In Fargo, families have been instrumental throughout the development of the Region V Partnership. They participate at every level, from planning to hiring personnel. Relationships are based on mutual respect and honesty. They share a willingness to try things differently and do whatever it takes. Family support is encouraged, as demonstrated by the community's success in founding a chapter of the Federation of Families. Important players, including the school district Special Education Director, support these ideas and have helped make a difference for children and families.

The Region V Partnership provides services primarily to children under the age of 20 with a current focus on 12- to 14-year-old boys and their families. The population served is 76 percent Caucasian and 24 percent Native American. Approximately one-half of the families are single-parent households. Although 65 percent of the referrals come from Fargo, six counties (Cass, Ransom, Richland, Sargent, Steele, and Trail) are served by the Partnership.

Referrals can be made by parents, guardians, or professionals involved with children who have emotional or behavioral difficulties. These children must demonstrate the most complex needs and be at risk for being removed from their home. Criteria for admission into the program are the same as those in Bismarck.

SOUTHWEST DETROIT COMMUNITY MENTAL HEALTH SERVICES, INC.

Detroit, Michigan

The Southwest Detroit Community Mental Health Services, Inc., is based on the wraparound philosophy and is a private non-profit organization. Ninety percent of the services are provided under contract to the Detroit Wayne County Community Mental Health agency. This community was nominated by the technical assistant for the urban grant communities for the innovative way that it involves families and community groups in the service delivery system.

In the past five years, the continuum of services for children has expanded to include not only out-patient therapy and screening for psychiatric hospitalization, but also a full continuum: early intervention, prevention programs, evaluation and out-patient treatment, home-based clinical work, intensive and assertive community treatment programs, respite care, crisis intervention, residential treatment, hospitalization, and family counseling. The wraparound program includes outpatient and early intervention services, prevention, and home-based treatment as part of the overall program.

The target population for this program is the southwest corner of Detroit, which has a population of approximately 105,000. Southwest Detroit is the most diverse area in southeast Michigan. The area has a very strong traditional Hispanic influence. It is a center for employment among the Hispanic population as well as a center for Hispanic cultural institutions and churches. This population is culturally and racially diverse, however. Approximately 20 percent of the community is Hispanic; 30 percent is African American; 40 percent is European American; and 15 percent is multiracial or made up of new immigrants from Asia, the Middle East, and Eastern Europe. The community is described as a place where new immigrants can start over.

GUILFORD INITIATIVE FOR TRAINING AND TREATMENT SERVICES SITE (GIFTTS) GREENSBORO, NORTH CAROLINA

GIFTTS serves the single county of Guilford, which includes two major cities, Greensboro and High Point. The county's total population is 387,000. The GIFTTS Project is based in the Guilford County Mental Health Center. Integration of the GIFTTS Project's System of Care Principles is under way in that agency, as well as in other public agencies in the county. The target population for GIFTTS includes

- children who are residents of Guilford County,
- children who are separated or at risk of separation from their families,
- children who need help from more than one agency to meet their unique needs, and
- children who are experiencing serious emotional or behavioral problems.

Because Guilford County encompasses two cities, the resources available to children and families are plentiful and include multiple choices of outpatient providers (individual, marriage, family, reactive attachment, substance abuse, etc.), in-home intensive therapy/family preservation, sexual offender and victim's treatment, crisis respite services based on a family model, residential treatment and therapeutic foster care, mentor programs, case management/service coordination, evaluations (medical and psychological), medication monitoring, and more.

Despite the variety of available services, agencies and providers in the past have not coordinated well with each other or with families. The System of Care movement and the GIFTTS Project have served as frameworks for involving parents at all levels of their child's treatment planning. The work with the Mental Health Association, the private, non-profit organization that is helping parents develop an advocacy organization for parents of SED children, is preparing families for this role. Additionally, GIFTTS is bringing children and families, community, and providers to the table together to better identify needs, treatment interventions, and strategies that result in a comprehensive child and family plan.

MULTIAGENCY INTEGRATED SYSTEM OF CARE (MISC) SANTA BARBARA, CALIFORNIA

The mental health system in Santa Barbara was established approximately 33 years ago in specific response to California state legislation for improved community mental health services. In 1994, Community Mental Health Services (CMHS) awarded a grant to this host agency, which after one year of planning resulted in the initiation of services by the Multiagency Integrated System of Care (MISC) in September 1995. MISC is located in Santa Barbara, California, and serves a countywide area with 400,000 residents,

25 percent of whom are children. MISC manages three clinics throughout the geographical area and employs 170 staff from 11 agencies. Of these, approximately 80 are employees of Alcohol, Drug and Mental Health Services. Today, the program serves as the lead agency in a multiagency System of Care.

The System of Care offers a large array of professional and paraprofessional services, which are coordinated across multiple agencies. One hallmark of the system is that clinical as well as administrative services for all agencies, including Child Protective Services, Probation, Mental Health, Public Health, Drug and Alcohol Treatment and Child Abuse Prevention, are co-located in one building. Communication and collaboration are enhanced as a result. This configuration benefits families and provides a "high level of high-intensity service, quickly and without bureaucracy." The stated purpose is to promote a greater level of child/family "competence."

Another hallmark of the system is what agency personnel refer to as the "no eject, no reject" policy for referral. All child-serving agencies within the service area can refer children and their families into the system without fear of rejection. Moreover, once children have been admitted for service to the System of Care, they will be discharged from service only if they reach the age of 18, move out of the geographical service area, or voluntarily leave the system.

A continuum of service is offered, with no one service being stressed. The right fit or "precision" of fit between services and each individual family is emphasized. Although the collaborative continues to struggle with how best to achieve this fit, the use of systematically collected and distributed outcome data has brought increasing success. Three basic data elements are examined by agency personnel: individual family characteristics at the time of intake; types and amounts of service delivered to each family (as well as aggregated information for all families); and specific child outcome data with aggregated data for all families served for purposes of comparison.

Data systems were developed in collaboration with the University of California Santa Barbara (UCSB). It is important to note that $200,000 of the agency's annual budget is specifically contracted to UCSB to develop systems to generate and manage outcome data. It is this use of outcome data that was behind the nomination of this community by the technical assistant for the small city/county grant communities.

COMMUNITY WRAPAROUND INITIATIVE (CWI), THREE TOWNSHIP SITE, OAK PARK, ILLINOIS

The CWI in the Three Township Site (Lyons, Riverside, and Proviso) in Illinois was nominated by the technical assistant for the small city/county grant communities for its innovations in involving family members in service delivery. Specifically, family members are put in a position to help other family members

and staff and to be liaisons between families and their wraparound team providers. The technical assistant reasoned that families are able to hear things from each other because of their shared circumstances, whereas they may be less able to receive the same comments from service providers. In addition, the CWI has created a concrete definition for Parent Advocates and is now trying to certify them through training and support to help them fulfill that role.

CWI is different from the other grant communities studied and from most other providers funded by the Center for Mental Health Services (CMHS) in terms of structure. The director of the grant community explained that he is the coordinator among township, county, and state regional mappings that relate to mental health services. He explained:

> *The Illinois model is really a confederation of community-based agencies and special ed co-ops. The thought was more of organizational effectiveness models of change. Where the grant structure really was a structure brought up against a group of community agencies to act as a catalyst in helping them to develop into a System of Care. That model in Illinois is congruent with another structure in Illinois. When the 1994 mental health plan was written, the whole state was re-mapped by the office of mental health into 62 local area networks or LANs. Our site comprises two of those LANs, 57 and 60.*

In 1994, the state child welfare agency set up the Local Area Networks (LANs) to decentralize control and the development of resources for children with serious emotional disturbances and their families. The agency also established a community effort that brought together parents, mental health workers, child welfare workers, juvenile justice workers, and educators to facilitate planning at the local level. At the same time, the state gave each LAN a prescribed amount of money for flexible funding, which allowed each LAN to provide nontraditional services to children with serious emotional disturbance and their families.

Given its community focus and emphasis on planning at the local level, the wraparound program served as a model for the local area networks as they developed a System of Care. As the Center for Mental Health Services grant draws to a close in the grant community, the administrative structure of the grant purposefully collapses and the functions of the administration are absorbed by the LANs. The director of the grant community explained,

> *So it's really more a catalyst that's brought around a group to stimulate their development into a System of Care. And then, out of necessity, it has to drop away, because the goal was not ever to set up another institution, or a subspecialty, or anything like that.*

The tasks at hand for the Community Wraparound Initiative include discussing and planning how to sustain the various professional roles, such as the Family Resource Developer, the grant has brought to the system and the other critical elements in the changing administrative and funding environment. In addition,

the Initiative must decide how to handle evaluation at the level of the LANs, by looking to the grant-required evaluations for guidance about which tools to keep and which to develop and by keeping in mind what will be meaningful to the families.

APPENDIX B: BENEFITS OF PARENT INVOLVEMENT IN STUDY

EXPERIENCES OF OUR PARENT PARTNERS

Two parents of children with special needs participated in all aspects of this study as research assistants. From designing the study through preparing this monograph, these parents have been essential to the efforts of the study team. In recognition of their role and contribution, as well as the importance of conveying not only what they gained from their experience but their own perspectives of their contribution, they were asked to share their experiences. Eloise Boterf and Tracie Goff have kindly agreed. The names of the children have been changed to protect their privacy.

STORIES OF MOTHERS CARING FOR CHILDREN WITH SPECIAL NEEDS

Parent 1: Eloise is a single mother of two children with special needs.

I am a single parent and have two children with special needs. Both my son and my daughter have been diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). My son has done quite well at home and at school since he began taking medication the summer before he started kindergarten. Prior to taking medication...he was unable to remain still at any time and could not settle down from stimulating activities. He was very impulsive and easily frustrated in every area of functioning. He still has some problems with frustration, but he does not exhibit these behaviors at school or in after-school care.

My daughter has also been diagnosed with Obsessive Compulsive Disorder, Oppositional Defiant Disorder, and Intermittent Explosive Disorder, and she has learning disabilities. She has a very high I.Q., which unfortunately makes it difficult for professionals to recognize and understand her deficits. It also enables her to be very creative and constantly at risk of harming herself and others, when exhibiting inappropriate behaviors. She has been receiving Exceptional Service Education (ESE) services from the school system in classes for children with Specific Learning Disabilities (SLD) for the past three years and Emotionally Handicapped (EH) services for the past year.

Parent 2: Tracie is married and the mother of a son diagnosed with ADHD.

I too have a child with behavioral problems…Mark, who is diagnosed with ADHD, Obsessive Compulsive Disorder (OCD), and Over Anxious Disorder. I struggle daily to accomplish normalcy in the home. I wish that I had been offered some of the services this family (i.e., being interviewed in the study) was receiving. I can't imagine how different my life would have been. I have been forced to focus on negatives so often by teachers, family members, and society in general.

BENEFITS OF HAVING PARENT PARTNERS IN THE STUDY

Parent partners helped ensure that the study was culturally appropriate and family friendly; specifically, they saw that the family invitation flyer and the interview and focus group guides used language that was family friendly. Families interviewed for the study also identified and connected with our parent partners.

Eloise: I participated and contributed to the development of the invitation to families to participate in this study. I helped develop language that was friendly toward families. I also helped in the wording and ordering of the questions that would be asked during the family interviews. I helped develop language that would be easily understood by families and would not be misleading in any way. We (parent partners) also developed the wording for the questions we would ask to determine demographic information about the families. Here also, I helped to word things so they would not be offensive to families and ensured that the way things were phrased was easy for parents to understand.

One parent (being interviewed) had some difficulty with English and seemed to be put off by my teammate (professional interview partner). She also treasured her privacy and was hesitant to discuss the violent behaviors her son exhibited at times. I was able to give her words that were simpler for her to understand, and I also shared that my daughter was violent at times. This really helped her open up and become much more comfortable with sharing with us.

Tracie: I believe that as a parent on this team I have given insight to the sensitivity of questions that would be asked during our research with SED parents. Most of all, in my being part of the research team, I gave a sense of ease to the parents we interviewed. I let them know that I was a parent team member. I too have a child with behavioral problems.

Parent partners gave the entire research process a real-life context, ensuring that the realities of everyday life faced by the families participating in the study were not overlooked.

Eloise: Parents like me have little available time to spend in any activities outside of caring for their child, and they usually are tired of being asked the same questions over and over again, which still does not lead to the help that they need. The invitation (which I helped develop) assured parents in our study that the entire process would be handled in a way that was most comfortable and convenient to them, and it also showed that we knew their time was valuable and we were willing to compensate them generously.

The experiences and expert knowledge of our parent partners resulted in more comprehensive data analysis. Their contribution increased the accuracy of the data analysis because of the personal experiences they shared with the families.

Eloise: As my teammate and I began to write up the brief analysis of our interviews, I was able to explain what some of the medications these children were taking were typically used to treat. Of all the medications reported to have been given to the children in our families, there were only about two that my daughter had never been prescribed.

Tracie: I also was able to define the family perspectives on emerging themes that otherwise might have been misinterpreted. There is a lot to be said about firsthand experience in the study.

BENEFITS OF THE STUDY TO THE PARENT PARTNERS

Parents reported that through their participation in the project, they developed both their professional skills and their leadership skills.

Eloise: Upon my return to Tampa (from traveling to do interviews), Dr. Armstrong continued to introduce me to other professionals at FMHI, who have influenced me to become involved with the Federation of Families for Children's Mental Health (FOFCMH) and the newly awarded THINK grant they received. I am now a member of the local chapter of this organization and chair the newly formed respite committee. I was just recently able to attend the annual conference of the Florida Respite Coalition because of my membership and chair responsibilities with the FOFCMH, which provided the funds for me to attend. I am also very involved with the Strategic Planning Committee of the THINK grant, and I will be part of the committee that will review the proposals of providers in our area who wish to become a part of the System of Care we are developing for Hillsborough County.

Parents reported that through their involvement with the study, their network of supports has expanded.

Eloise: I was able to learn a great deal about the availability of respite for families throughout the state and how these programs were set up. I also made many new contacts with other parents and professionals that will benefit the Federation and my own personal life with my child.

Parents reported gaining skills in their ability to advocate for their children.

Eloise: All of these activities have allowed me to connect with parents and providers who are helping me advocate better for my child's rights in the school system and obtain other needed services for her. I am slowly beginning to be able to persuade my daughter's school to at least provide more in-depth evaluations of her specific needs for services in the school. This has been a major struggle for me throughout my daughter's attendance in the public school system. In summary, my involvement with Promising Practices has been very positive and rewarding for me. I have been empowered not only to advocate effectively for my own children, but also to advocate in my community to provide more appropriate and more accessible care for all children with emotional and developmental disabilities.

I have also been able to learn more about the medical needs of my child and have become much more proactive in her treatment.

Tracie: Being included in the Promising Practices study has allowed me to express my feelings about the difficulties of living with a child with behavioral problems. I have developed a yearning to continue my studies and efforts to educate and offer any services to parents with children like mine.

Parents have increased their knowledge of the System of Care, the needs of children with emotional and behavioral disorders, and the value of focusing on the accomplishments of a child with behavior problems.

Tracie: On March 8, 1999, I sat at my dining room table answering questions rabout my son Mark's successes in life. Mark, who is ADHD, OCD, and diagnosed with Over Anxious Disorder, has accomplished successes in my eyes. A mother's eyes. I never thought I would be sitting with someone, anyone, discussing the successes of my son Mark. I have been forced to focus on negatives so often by teachers, family members, and society in general that I did not realize what a pleasure talking about my son could be. I felt myself glowing with such pride that I had never felt before. I thought to myself, "So this must be what it feels like to be one of 'those parents' with a 'normal kid.'" What a feeling. It was like a dream! It was a day I will never forget.

Eloise: Parent's hopes and dreams never really change when they find out there is something "wrong" with their child. Those dreams are there from birth. The only part that changes is a parent's expectations of realizing those dreams.

APPENDIX C: FAMILY INVITATION FLYER

PROMISING PRACTICES: EXAMINING THE SUCCESSES OF CHILDREN AND FAMILIES

FAMILY INVITATION

The University of South Florida would like to talk to families about the successes you have had with your child or children with special needs.

We would like to talk with you about:

- The services you have received that have helped you achieve these successes;
- The relationships you have had with service providers;
- Other supports that have helped you achieve these successes; and
- What kinds of things have kept you involved in services.

If you are willing to talk with us, the interview will take between an hour and an hour and a half of your time. You may choose the place that is most comfortable for you to do the interview, either in your home or another location.

You will be paid $30 for your time.

To participate, contact:

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